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ABSTRACT

Proceedings of a 1986 symposium on the education of children with low incidence handicapping conditions focus on medically fragile children, advocacy, and technology. R. Dwain Blackston enumerates conditions affecting medically fragile children, family needs and stresses, and guidelines for effective family-staff relationships. Responses by Frances P. Connor and Barbara Sirvis discuss related factors affecting educational programming, including teacher competence and management problems in the school setting. Frederick J. Weintraub, in "Action Agenda to Improve the Education of Low Incidence Handicapped Children," elaborates on such policy issues as a lifelong continuum of educational opportunities and quality of education. Responses by June Mullins and Anne L. Corn address the limits of educational responsibility by special education teachers and issues of special concern to teachers of blind and low vision children. Lawrence A. Scadden describes the impact of technology on visually impaired children and youth, while Gail McGregor focuses on the use of technology in educational programs for multiply handicapped students. A response by Samuel Ashcroft notes the need to reduce the gap between the state of the art and the status of educational practice in the use of technology. A concluding statement by Vivian Correa summarizes the symposium's professional contributions. (JW)

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CRITICAL ISSUES FOR LOW INCIDENCE POPULATIONS

Edited by
Frances P. Connor

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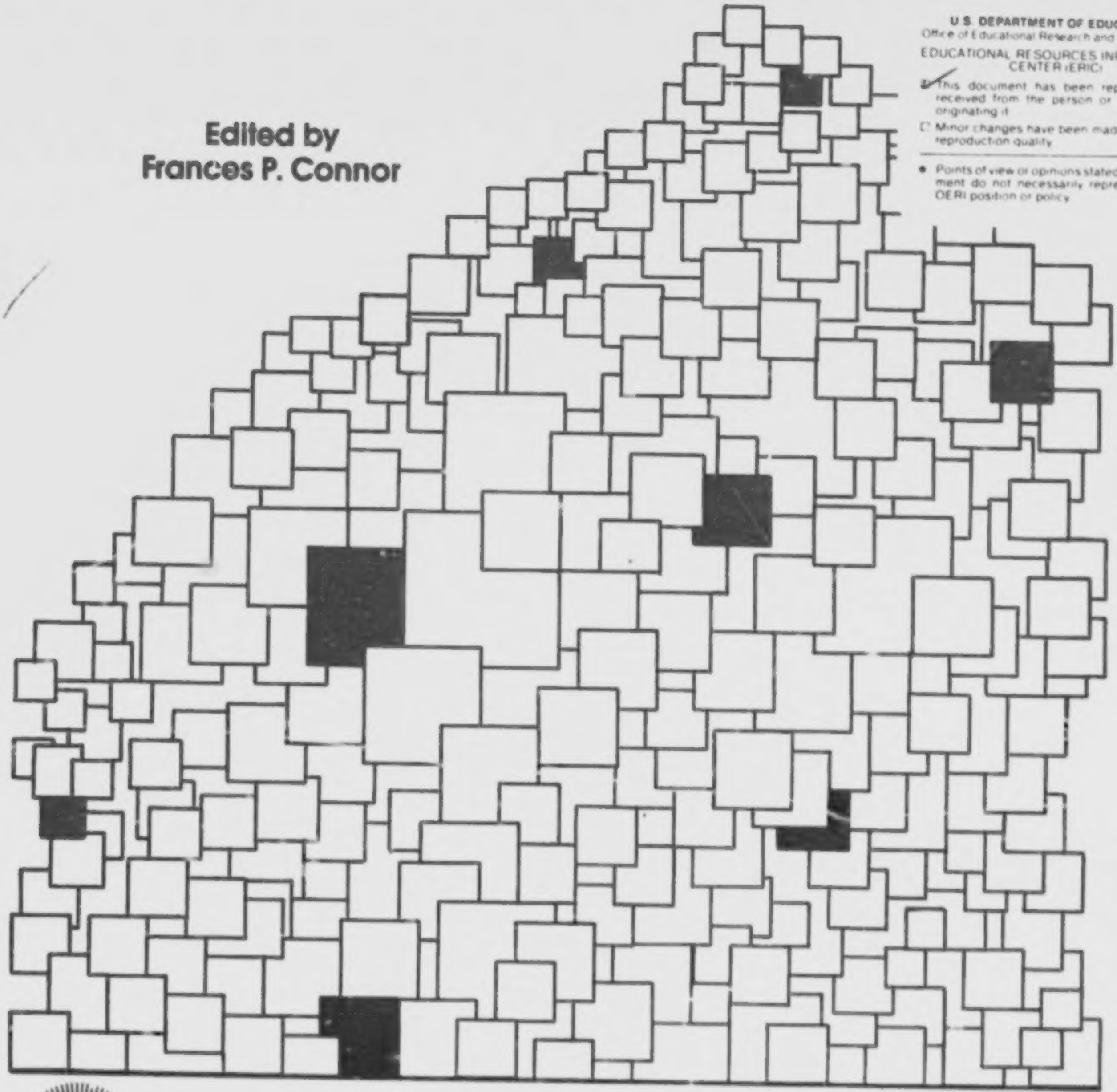

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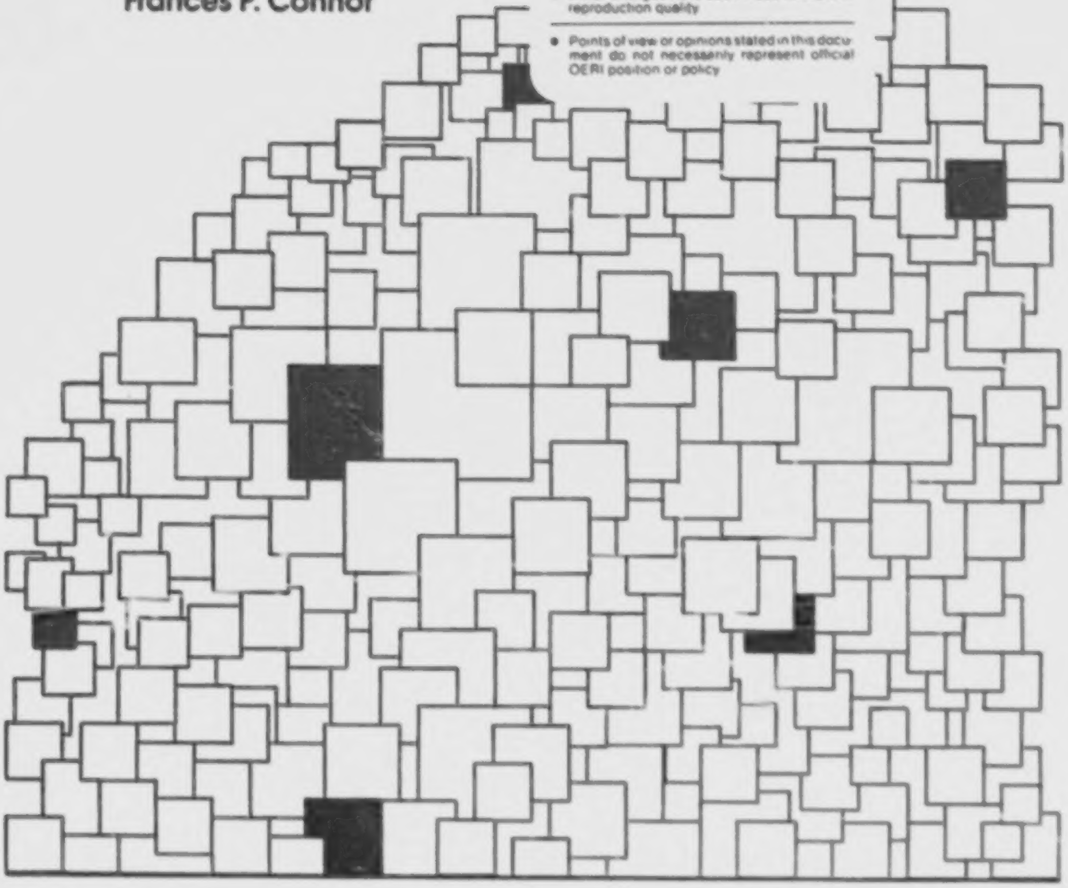

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INTRODUCTION

Frances P. Connor

Increasingly, in professional literature and policy making statements, special education appears to be equated with education of children with mild disabilities. However, as reflected in the divisions of The Council for Exceptional Children (CEC), there are "minority groups" within the broader handicapped minority.

It is clear that wherein a community has large numbers of handicapped children with somewhat similar educational needs and/or learning impediments, a full range of school settings can be made available to them within the local school district. But, the children addressed in this symposium are few in number and evidence a variety of unique and interacting characteristics requiring highly specialized instructional approaches, equipment, and personnel resources not readily available in community schools.

The symposium was designed to explore issues as special educators and other concerned professionals identified unmet needs of some children with low incidence disabilities. They discussed exemplary practices and proposed approaches to cut through or reduce some of the obstacles, particularly those related to effective communication, cognition, mobility, and social skills. They also were prepared to challenge current practice and unvalidated conclusions about the effectiveness of some highly publicized program suggestions.

Over 30 years ago, John Dewey bemoaned two major deficiencies in individuals educated in American schools. He felt they were unprepared for real life in two ways: first, most do not take responsibility for informing themselves of human issues that bear on our common interests, and second, even when aware of the issues, they lack the interest and/or confidence to take action.

Such was not the case for the planners of this CEC symposium on the education of children with low incidence handicapping conditions. Nor does it apply to the conference participants. Contemporary problems and issues were discussed openly; there were specific admissions that some content across exceptionality specializations was "new" to highly qualified special educators; instructional and organizational variables for consideration and recommended solutions were offered without fear of rebuff.

The national symposium concerned with contemporary major issues in the education of children with low incidence handicaps was held in Atlanta, Georgia, September 18-20, 1986. It was sponsored by The Council for Exceptional Children (CEC) and planned in cooperation with the Council's Division for Children with Communication Disorders (DCCD), the Division for Physically Handicapped (DPH), and the Division for the Visually Handicapped (DVH). The participants were from 30 states and included teachers, supervisors, educational administrators, and college/university faculty. Each person was, either directly or indirectly, serving children or youth with a low incident handicap; in general, the low incidence specialists had had relatively little opportunity to share professional concerns, program ideas, or practices with members of other Divisions since at national CEC conventions, divisions usually meet concurrently. Of particular note in the symposium were the opportunities for lively interaction among the 80 or so professionals.

The three foci of the symposium were medically fragile children, advocacy, and technology. The format called for a major presentation on each topic. The four keynote addresses were followed by responses from designated division members who provided challenges, elaborations, and/or varying points of view. The participants met in small groups across divisional interests to discuss both the content and implications of the presentations. Based on the speakers' provocative subject matter, responses, and small group interactions, participants' conclusions, questions, and identified areas for research, a stimulating, well conceptualized statement was presented by an invited specialist. This concluding statement highlighted and integrated problems and trends identified from the formal and informal professional interactions.

While the issues addressed in the sessions were at times directed toward the concerns unique to a division's special education populations, much of the content was applied across divisions. It was evident that issues related to medically fragile children, advocacy, and technology were by no means division specific. Rather, the participants across divisions highlighted the problems raised, the issues which emerged, and the solutions which were proposed. They unearthed sensitive problems and directed attention to new challenges and to some nontraditional ways of approaching critical program needs of low incidence special education students.

This publication contains four sections. Each is devoted to a general session and subsequent discussion. The first three parts include the major presentations on the assigned topics, and the responses to them by several division members. The fourth chapter is a culminating statement.

The first speaker, R. Dwain Blackston, M.D., from Emory University School of Medicine, discussed the numerous medical, developmental, and neurologic problems of medically fragile and vulnerable children. Important to the participants were his emphasis on the roles of families as the primary caregivers and on the carefully prepared individualized program plans required by medical staff. Samples of a nursing plan and extensive information on critical management procedures required for children with myelomeningocele (spina bifida) were made available.

In considering the topic of advocacy, Frederick Weintraub, Assistant Executive Director of CEC, brought the conference group up to date on recently passed and pending legislation, particularly the 1986 amendments to P.L. 94-142, including the new national commitment to comprehensive programming for infants and toddlers with handicapping conditions. His message to special educators was clear; their advocacy roles were convincingly and realistically addressed.

The third topic, technology, was particularly informative, especially for individuals without recent preparation in the use of new and improving technology and adaptive equipment to enhance communication, mobility, and general performance of children and youth with disabilities. Lawrence A. Scadden of the Electronic Industries Foundation opened the third general session with a presentation of the impact of technology on visually impaired children and youth. His experiences and scientific background highlighted the session. The second keynoter during this session was Gail McGregor of the Johns Hopkins University. She concentrated on the use of technology in educational programs for students with multiple handicaps. Following this section are lists of resources which should aid personnel who are planning and implementing programs utilizing technology appropriate for some children with low incidence disabilities.

Would that it were possible to include in this report the abundance of audiovisual material used to depict unusual problems or to describe clearly the use of technology by responders as they described complex programming for students with unique needs. Of assistance in this regard was the concluding statement for which Vivian Correa from the University of Florida conceptualized the symposium's professional contributions. She extracted issues, clarified challenges, and addressed implied problems and professional options.

Major contributions of the Division for Children with Communication Disorders were made through audiovisual presentations of alternate modes of communication, particularly those effective in the education of children with severe hearing impairment. Since the content cannot be clearly presented in narrative form, these proceedings of the symposium do not adequately reflect the planning and participation of the division.

This report is a collection of presentations made by the invited speakers together with responses from representatives of the three CEC divisions. Not clearly reflected are the stimulating discussions across disabilities which were heard in the organized small working groups and during the informal gatherings between sessions. It was during these interactions that specialists in visual impairment, for example, were hypothesizing about the effects of applying positioning principles to their students. Similarly, a teacher of young chronically ill children sought ways of employing the tactile approaches so successful with a child without functional vision. The sharing of materials, of research papers, and of information dealing with financial and technical support was an unexpected outcome of the symposium.

Several emphasized topics are worthy of further exploration. Among them was the awareness that theory and practice identified with one area of exceptionality can be modified and applied, at least experimentally, for another low incidence group. Educators sought assistance from other highly qualified specialists as they considered their student assessment program planning, and progress evaluation. There appears to be need for a cross-specialization model for teachers of low incidence populations. Such an intra-disciplinary approach is comparable to the transdisciplinary efforts espoused throughout the meetings.

The conferees were deeply committed to finding means of differentiating further the ways by which their students can increase their repertoire of skills for use in a variety of situations. Concern was expressed about educators' apparent satisfaction--or complacency--that legislation enabling an appropriate education for all handicapped children exists. Therefore, throughout the symposium, there were open-ended suggestions for as yet untried extensions of present practice which could have potential for accelerating a child's breaking out of traditional restrictions and depressed expectations for his or her accomplishments. The search for alternate routes toward increased participation of these students in the general world of active childhood and satisfying adult living permeated the deliberations.

Throughout the symposium, much attention was given to identifying methods of encouraging interactions with parents, concerned citizens, the business community, influential professionals, and the students themselves in order to effect change. The principal objective was to facilitate active participation in a world accustomed to sheltering and excluding individuals with health and/or severe sensory problems. Acknowledged also were the educational roles of the various constituencies and social structures as well as their critical advocacy functions in promoting the highest quality of program possible.

The power of new and developing technology is clearly presented in the statements which follow. The participants varied in their competence in computer use; they also demonstrated wide gaps in their knowledge of the roles technology does and will play in the education, health, and daily living skills of children with low incidence disabilities.

The purpose of the symposium, that is, the identification and discussion of some critical issues related to low incidence populations, was truly met. There was no intention of melding the three disability groups into one category. Rather, common concerns were explored and efforts to learn from each other through translation of workable constructs and specialty consultations were promoted.

THE MEDICALLY FRAGILE CHILD

R. Dwain Blackston

The fragile or vulnerable child syndrome was first described over 20 years ago by Green and Solnit in relation to preterm infants who required prolonged initial hospitalization. Despite the infant's recovery from his first illnesses, parents often perceived him as fragile, vulnerable, different, and with needs that warrant special status in the family. These beliefs may adversely affect the behavior of both the parents and the child.

VARIETY OF CONDITIONS

The medically fragile child may be identified as having a number of conditions that require special technology, unusual treatment plans, and special feeding devices and diet, as well as cardiac and respiratory monitors. Included in these conditions are chronic lung problems such as bronchopulmonary dysplasia (BPD), chronic asthma, cystic fibrosis, congenital malformations, and neuromuscular diseases such as the Werdnig-Hoffman Syndrome. These conditions may require ventilator assistance, long-term tracheostomy, continuous or as-needed oxygen, pulmonary drainage, and frappage. Congenital heart disease with its associated problems of monitors, continuous medications, breathing problems, and easy fatiguability comprises another category. Feeding problems, failure to thrive, gastroesophageal reflux, and short bowel syndrome secondary to necessary surgical removal present special needs for adequate calories and diet through nasogastric feedings, G and J-tube feeds, total parenteral nutrition through central lines, and appropriate positioning. Neuromuscular diseases such as spina bifida, hydrocephaly, and muscular dystrophy present special needs such as wheelchairs, daily physical and/or occupational therapy, splints, palliative surgical procedures, bladder and bowel collection and control. Other chronic disabling conditions which fall into the fragile or vulnerable child syndrome include hemophilia, brittle diabetes, severely disabling genetic disorders such as trisomies 18 and 13, persistent seizure disorders, and osteogenesis imperfecta (brittle bones). Near-drowning victims and serious trauma secondary to accidents, often vehicular, round out the usual listing.

INFANCY

To understand the medically fragile child it seems logical and helpful to consider the beginning neonatal and post-neonatal periods. Improvements in newborn care and technology have markedly increased the survival rate of low birth weight infants, particularly those weighing less than 1,000 grams (2.2 lbs). About 18,000 very low birth weight infants are born annually in this country; their survival rates are as high as 70-80%. Low birth weight babies comprise a disproportionate percentage of children at high risk for medical, developmental, and neurologic problems. Among the serious conditions that may afflict these preterm infants are the aforementioned bronchopulmonary dysplasia (BPD), intraventricular hemorrhage, retinopathy of the premature with blindness, and post-tracheostomy complications.

Important to educators are the meaning of BPD, its sequelae, and management problems. In general, patients with BPD remain oxygen dependent for more than

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28 days following mechanical ventilation during the first week of life; their persistent lung changes can be seen on X-ray. Many of these children require mechanical ventilation and oxygen therapy for weeks, months, years; they may also need tube feedings. Children with BPD have respiratory failure with varying degrees of hypoxia. While many infants demonstrate improved respiratory function with weight gain and age, others have persistent reactive airway disease with wheezing, recurrent infections, and airway obstruction. Because of their need for supplemental oxygen, the hospital stay for these infants is often very long and readmission frequent.

FAMILY NEEDS

Infants with vulnerable conditions have special needs, but so, too, do their families, particularly their parents. Effective parent communication and necessary education must begin early to enhance the family's abilities to comprehend, cope, and sustain.

On the basis of clinical experiences, several practical guidelines have evolved. They have been effective in family-staff relationships. The following principles need emphasis:

- Be available to families and plan to spend more time with them than usual.
- Be aware that going home from the hospital is frightening and understand that parent and child anxiety is normal and that their energy can be positively directed.
- Be supportive, open, sensitive.
- Give brief, accurate information with continued clarification.
- Encourage parents to be in control and to structure their lives in order to reduce stress without being partronizing.
- Expect some anger from parents of the vulnerable infant, and stress the normalcy of anger.
- Offer consultation to relatives and others whose behavior influences the parents' resolution of problems.
- Be adaptive in working with different family styles.
- Be prepared to confront your own feelings of helplessness in order to provide adequate support to the family.
- Seek help from other professionals when you feel overwhelmed or cannot decide if the family is coping adequately.

A congenital condition such as myelomeningocele (spina bifida) is well known to preschool and elementary educators for the multiple complications faced by the child and the complexity of his or her special needs, including individualized equipment, medications, and therapies. Briefly, spina bifida appears most commonly as a cystic protuberance of the lower back with tethering (disruption) of the spinal cord and resultant loss of nerve supply and diminished function below the level of the lesion. Difficulties with bowel and bladder control, recurrent urinary tract infection, loss of muscle tone in the legs are sequelae. It is not unusual for an associated lesion of the cerebellum to cause hydrocephalus (water head). Thus, part of the treatment may include neurosurgical repair and shunting of fluid as well as possible bladder and orthopedic surgery. Physical therapy, assisted ambulation, skin care, and positioning are also part of the picture. Spina bifida is common, occurring, for example, at a rate of almost 1 per 1,000 live borns in North Georgia. There are several attachments which delineate the comprehensive care of the child with spina bifida.

If health care and educational plans are to be developed for chronically ill, medically fragile children, there is a need to recognize a number of issues that confront these families regardless of the child's specific condition. Daily care of the child is often extremely stressful and the disease's course may be highly unpredictable. In addition, treatment and education regimes are at times complex and conflicting. Important to planning for the children is awareness that the treatments themselves may be arduous, painful, and even embarrassing. In some instances, the disorders are accompanied by continuous pain and discomfort. Concurrently, the families may encounter excessive fatigue, marital stress, low family morale, reduced career mobility, and poor sibling adjustments. School participation by the medically fragile child is affected. Diminished school performance and social adjustment may well result in frequent absenteeism, low energy, and need for health care while at school. Uncertainty regarding future education and vocation is also common in the fragile child. It is therefore not surprising that a family may have critical reactions to their vulnerable child's chronic illness. Staff should be alert to signs of disappointment, shame, guilt, resentment, anger, overprotectiveness, overindulgence, overrestrictiveness, sibling tensions, and overinvestment in the sick child with resultant underattention to a marriage partner and other children. If the health and education professional understands these reactions, developing the necessary plans for parent and sibling support for their involvement in care plans and for necessary relief and respite for the family can be more realistic and effective.

AVAILABLE PROGRAMS

Fortunately, many programs are available and more are being developed to provide medical day care for the vulnerable fragile child as an alternative to prolonged hospitalization. This day care allows the child to be in a home, that is, a normal life setting. Furthermore, this approach is quite cost-effective. At the same time it provides parents with the opportunity to continue their careers and their ability to support their child through health insurance. It cannot be overemphasized that day respite and the chance to work are extremely supportive if not truly therapeutic. As health and education professionals we must understand and encourage this "normal balance" for parents. If one enhances independence and self-support for parents, it can be expected that this balanced attitude will also be conveyed to the child, his or her caretakers, and the total family.

Medical day care employing a multidisciplinary approach is a reality for many chronically disabled children and is available through a variety of facilities. Many of them are privately run. Such programs can be found as part of children's hospitals or as part of general hospitals. Still others are established as pediatric home programs. Exemplary programs which treat children with such complex needs as ventilator assistance are found in the Children's Hospitals in Philadelphia, Boston, Washington, and Chicago. Excellent community based programs are available through the Pediatric Home Care Program at Albert Einstein College of Medicine in New York which services inner city children and Project REACH (Rural Efforts to Assist Children at Home) in Central Florida. Whether private, hospital affiliated, or community based these programs are funded through private insurance, Medicaid, with the Medicaid waiver a great help, and contractual arrangements, often with state Crippled Children's or Children's Medical Service programs. A multidisciplinary team approach is is used by all these programs.

Of particular interest is Medi-Kid, Inc. an innovative program in Jacksonville, Florida. This program has particular appeal since it is geared to meet the needs of preschoolers (birth to 5 years). It is designed to offer service, family support, and instruction to parents, as well as to prevent many of the aforementioned health, school, and family problems. Attachment A presents the care plan for a child with bronchopulmonary dysplasia, seizure disorder, neurologic complications, and family dysfunction. This comprehensive care plan is similar to the individualized educational plan and would fit naturally with it to coordinate the work of the health and educational teams.

AN EXAMPLE

The increasing numbers of medically fragile children and their families will benefit from integrated and cooperative professional effort. The effort requires starting early, planning ahead, and thinking preventively. The following chronology demonstrates how a health team working with a large inner city hospital with a daily census of 45 neonatal, intensive care unit babies interfaces and coordinates with a public school program. First, the team attends the discharge staffing for the Neonatal Intensive Care Unit (NICU) graduate and plans ahead for the home and community supports, including earliest enrollment in a well-established educational program known as the Parent-Infant Program. Using a long-term case management approach to effectively coordinate the health and educational services is effective. Among the many positive, preventive results are included: higher educational achievement, prevention of secondary health complications, greater social and behavioral skills, and prevention of parent and sibling stress.

The role of the educator working with children with medical problems is a complex, often difficult one. The teacher is expected to understand the varied problems of the chronically disabled, fragile child which include: easy tiring, recurring pain and other symptoms, side effects of medication (anxiety, irritability, inattentiveness, drowsiness), and loss of skills which are disease related. These children are in need of an educational program designed to address these concerns, which may easily be overlooked or misinterpreted as behavioral, emotional, motivational problems. Too often school personnel report these problems as emotionally based, thus further compounding the feelings of frustration, inadequacy, and aberrance which the child and parent have so often experienced.

Educators have the unique opportunity to enhance the ill child's life. It is not unexpected that a well-structured school day may be quite different from a busy difficult-to-structure home. Therefore teacher support is important in helping parents avoid guilt and further anxiety when what works at school does not work at home. Teachers, through active participation in the health and social service support teams, can facilitate the parents' and the child's efforts to reduce the ability to thrive.

A society comprising multiple agencies and an often stifling bureaucracy is overwhelming to parents of medically fragile children as well as to physicians and teachers. It is my strong belief that if we as health and educational professionals can work closely together, focusing on child and family needs at the earliest time in a child's life, we can provide the best care plans and at the same time reap positive professional satisfaction. Granted, there will never be enough money to placate every agency or system, but have we looked at what we can do together through coordinating resources? With a true spirit and attitude of cooperation, public dollars can be saved and much of the human potential can be realized.

Attachment A: Care Plan
(Courtesy of Florida Medi-Kid, Inc., Jacksonville, Florida)

Nursing Diagnosis	Goal	Plan
1. Alterations in respiratory function secondary to: BPD; Asthma; Chronic Lung Disease (C.L.D.) related to: (A) Ineffective Airway Clearance; (B) Potential for ineffective breathing patterns; (C) Potential for impaired gas exchange.	Child will maintain pulmonary function or improve status as evidenced by: no hospitalization or reduce hospitalization for infections or complications; maintaining normal respiratory status (v.s., auscultation) or anoxia, or anoxia related anxiety or color change.	A. V.S. - HR and rhythm, R.R., quality q. day and prn, temp. prn. B. Evaluation of respiratory status q. a.m. and prn including: auscultation; anxiety; v.s.; color. C. Monitor for fatique and quiet child to decrease respiratory demands (quiet time/play). D. Aersol tx. as ordered: Terbutaline 1/ml in 2-3 cc NACl for 15-20- min q. 4 hr. 8 a.m.-12 p.m.-4 p.m. E. C.P.T. and Postural drainage as ordered q 8 hr. Observe for: improvement, document. F. Nasopharyngeal Suction prn and O2 on standby. G. Cardiac and apnea monitor, size 8 Fr. catheter (one per day) at all times when not under direct supervision. H. General - 1. maintain adequate hydration state. 2. change in health status, virus, etc. 3. high risk for infectious disease - keep isolated from any child with cold, etc.

Nursing Diagnosis	Goal	Plan
2. Activity intolerance related to alteration in O2 transport system secondary to Asthma, C.H.D., B.P.D. related to possible fatigue.	After identifying factors that increased fatigue, pt will not show s/s of exhaustion, fatigue (related to stress, increased activity, bath etc.) as evidenced by lack of sleep disorder, anoxia, color change, and will improve activity tolerance evidenced by increased periods of being awake and increased tolerance of normal activity.	A. Identify factors that increased fatigue (bath, suction, CPT, PT, OT). B. Plan daily schedule to provide adequate rest and sleep time. C. Reduce activity if s/s of anoxia (cyanosis, labored breathing, increased HR, increased RR). D. As child's resp. status improves, increase activity level (play and social stimulation) as tolerated.
3. Potential for anxiety related to possible decrease in gaseous exchange (anoxia).	Pt will remain anxiety free as demonstrated by pink color, normal v.s., no s/s of anoxia, and remains comfortable and calm.	A. Identify factors that cause anxiety. B. Dx. anxiety promptly (increased HR, increased RR, labored respirations, decreased airflow (suction secretions) diaphoretic, restlessness and anxious facial expression. C. Treat immediately with suction and O2 and stay with child.
4. Impaired physical mobility secondary to Hyptonic C.P. and wheelchair dependency (monotony of confinement).	Child will remain interested and active in his environment, will not show s/s of being bored and developmental advancement will stay as close to normal as is possible and will not develop complications associated with immobility (pressure sores, pneumonia, etc.).	A. In bed (HOB increased 45° and with posey) for 30-60 min. after feeding or in wheelchair - position change q. 2 hr while awake. B. Not in wheelchair for more than 2 hrs at a time. C. Floor activity on pallet. D. When OOB or wheelchair plenty T.L.C., music, social stimulation. E. Discuss with parents about keeping home environment stimulating. F. OT and PT b.i.d. 30 min. according to therapist's plan/program.

	Nursing Diagnosis	Goal	Plan
5.	Potential for diversional activity deficit related to bed or wheelchair bound.	Refer to #4	Refer to #4
6.	Potential for impairment of skin integrity related to potential immobility (Hypotonic C.P.).	Child's general skin integrity will remain healthy as evidenced by no tissue breakdown, infections, or pressure sores.	A. In bed only for sleeping, after feedings. B. Turn q. 2 hr. if immobile. C. Proper skin care, massage bony prominence to increase circulation etc. D. Proper body alignment and support for bony prominence. E. Early detection of complication and appropriate nsg. intervention.
7.	Potential for respiratory or GI complications secondary to being highly allergic.	Child will not show s/s of increased respiratory complications or digestive disorder related to known or unknown allergies.	A. Follow specific instruction of allergy M.D. (both dietary and other). B. Identify s/s of allergic reaction and try to remove the source (dyspnea/wheezing; increased cough, watery eyes and nose; hives/rash; erythema; edema). C. Careful documentation of circumstances and notify parents/MD as appropriate.
8.	Potential for alteration in nutritional needs (secondary to allergy).	Child shall maintain (and increase) growth (ht/wt) on prescribed hypoallergic diet and shall not suffer delayed G&D evidenced.	A. Plot ht/wt on graph on admission and evaluate wt. frequently q wk; if stable, 2 x wk if not. B. Choose high caloric foods first from prescribed diet.

	Nursing Diagnosis	Goal	Plan
9.	Communications impaired (lacking ability to say more than several distinct sounds) related to C.P.	Child will demonstrate attempts at vocal communication and thus decrease frustration due to inability to communicate.	A. Frequent supervision of child while awake q. one hr. B. All forms of communication: song; rhyme; talking. C. Treat child normally regarding language acquisition. D. Encourage support and praise each and every attempt to vocalize and mimic sounds or words.
10.	Sensory alterations related to partial vision impairment (can only see shadows and movement).	Child will not show s/s of deprivation related to decreased vision and will learn compensatory mechanisms for decreased vision as evidenced by happy disposition and normal (for him) development.	A. Talk to and tell location ("over here"). B. Increase other sensory stimulation, music, touch. C. Encourage any attempts at self care (drinking, feeding), assist, and praise.
11.	Potential for delayed G&D, secondary to C.L.D. and C.P. related to ongoing G&D deficits.	Child will grow and develop to his maximum potential as evidenced by status quo or improvements in G&D (improvement defined by growth chart, MD, OT and PT therapists).	A. Document baseline for G&D. B. Evaluate and plot G&D at 3-6 month intervals. C. Maintain OT and PT programs as ordered. D. Identify changes or needs for changes as indicated. E. Monitor caloric intake (c/kg) and notify MD if not increasing wt. F. Normal infant/child stimulation techniques and T.L.C. frequently.

Nursing Diagnosis	Goal	Plan
12. Potential for knowledge deficit; new prescribed tx: equipment, meds, diet management, growth and development etc.	Family will maintain optimal knowledge level, regarding current and future medical/nsg plans and protocol for as evidenced by no alteration in health maintenance.	A. Review current practices and knowledge prn, especially if problem is identified. B. As new tx, meds, equipment, etc. are instituted, develop teaching plan and initiate such plan. C. Think in terms of normal G&D and stay ahead with preventive education (safety, immunization, advancing diet, etc.).
13. Potential for impaired home maintenance, management (mom's complicated pregnancy) or alteration in child care.	Family will maintain proper home management of child evidenced by stability of both emotional and physical health of family and child; and as conflicts and problems arise, they will feel comfortable to discuss it with staff at center.	A. Provide for communication and nonjudgmental atmosphere. B. Frequent evaluation of how things are at home. C. If problems arise and are identified, make suggestions for decrease of complications, support attempt to cope. D. Referral to appropriate support service.
14. Potential for parents' feelings of powerlessness: future hospitalizations and episodic crisis.	Parents will maintain a sense of control over future and present circumstances as evidenced by a positive attitude and a sense of self-worth demonstrated by parents.	A. Staff to continuously foster parents concept of self-worth and credibility. Examples: o Praise parent's job with child. o Take suggestions from them and follow through if possible. o Compliment parent--compliment child. o Always try to reach parent when consultation is needed or a crisis happens (phone). o Keep parent abreast of any changes and the reasons for them.

Nursing Diagnosis	Goal	Plan
15. Potential for social isolation related to equipment dependency (parent and child).	Child and parent will not suffer social isolation as evidenced by parents' ability to get out of home and be relieved of giving chronic care and child will continue to develop normal socialization skills (social smile, awareness of others).	A. To be maintained at Medi-kid 5 days/wk. B. Foster mother's feelings of leaving child here for a break as OK. C. Child and staff socialization q. one hr. while awake and to play with well children daily.

A RESPONSE

Frances P. Connor

Dr. Blackston described clearly the medical status and treatment of the medically fragile child, particularly the one who requires prolonged or intermittent hospitalization. His slide presentation of children's problems and interventions together with a highly individualized and comprehensive nursing program would certainly be welcomed by teachers working in pediatric or rehabilitation hospitals. How gratifying it would be for special educators to be able to share with colleagues from other disciplines their assessments of a child's educational and social function, their educational goals and objectives, and the actual plan of action to be followed. How stimulating it would be to interact with specialists from related disciplines regardless of the setting in which the child might happen to be.

It is obvious that the symposium's participants appreciated the nursing program plan as presented; they obviously see it as a model--as an important asset for a teacher in a children's hospital or rehabilitation center. A parallel IEP prepared by the special educators together with plans presented by various therapy staff members would certainly provide evidence of clear, precise, and broadly based assessment of the child's needs, his or her specific program objectives, the procedures to be followed, and the means by which achievement can be measured.

But intense action upon or on behalf of a child by a number of different staff members can be problematic. Thus, it is strongly urged that there be role assignments and integration of the necessary strategies and/or interventions with recognition of who, on the staff, might most easily and effectively assume the specific roles.

When staff members understand the work of colleagues, a transdisciplinary approach can be the most economical and appropriate for ill children, especially for those who have difficulty dealing with a large number of well meaning adults. The approach requires (1) one professional to relinquish his or her role to another colleague in some instances; (2) a professional to assume a role(s) traditionally performed by members of another professional specialty; (3) supervision of the intervention by the one qualified by training and experience to carry out the treatment; and (4) the continuing effort to increase the body of knowledge and skills in one's own professional field (Connor, Williamson, Seipp, 1978).

After each professional representative designs the individualized program plan in his or her specialty, a comprehensive integrated plan can be cooperatively developed and implemented for efficiency and for the comfort of the child. In working with medically fragile children, a carefully planned program for the child's family is also critical. One is reminded of Tolstoi's statement that "All happy families resemble one another; every unhappy family is unhappy in its own fashion." The families of medically fragile or chronically ill children certainly encounter unique sets of issues and untraveled pathways; they require individualized program plans to assure appropriate staff support to the whole family.

Medically fragile children are growing in number and are presenting increasingly complex challenges. Yet, they are living, often lively, children. They are like all other children in their basic needs, their rights, and their humanity. Without close cooperative efforts between knowledgeable medical and educational personnel, the realization of the ideals of a free, appropriate education in the least restrictive environment for this population is in jeopardy.

The intervening variables are numerous. As indicated by Hobbs, Perrin, and Irays (1985), over one million children under 17 years of age have severe chronic illness and most of them will live until adulthood. These children have reduced levels of activity and average between 25 and 100 days per year in bed. As discussed in a 1983 report of the Child Life Council, illness and hospitalization negatively influence a child's general development, particularly his or her self-concept as well as emotional and social being. Limited mobility, pain, curtailed personal interactions and restricted general experiences all are part of the child's life style. The relationship between chronic illness and depressed later achievement has been documented by Pless and Pinkerton (1975) and Rutter, Tizard and Whitmore (1970).

THE YOUNG CHILD

The efforts described by Blackston to reduce the time medically fragile children must live in the sterile hospital environment are encouraging. For example, he discussed the increasing number of medically directed day-care facilities and foster homes which are available to vulnerable children. These programs are obviously more cost effective than long-term hospitalization and they allow the young child to live in a home--a family-like setting. In many instances, the medical foster home is the home of a nurse who can provide the necessary medical monitoring.

Of major concern to an educator is the apparent lack of responsiveness to the special needs of medically fragile children who live in poverty and/or are from minority groups. The relationship between low socioeconomic status and later low academic achievement was clear from maternal teaching strategy (Bee, Van Egeren, Streissguth, Nyman, & Leckie, 1975); the relationship between the mother's (or caregiver's) educational level and the child's later school achievement have been demonstrated (Ramey & Campbell, 1982).

SOCIOECONOMIC STATUS

The increase of low birth weight babies at high risk presents a new group of children with special problems. The need for early intervention to facilitate the development of children in impoverished conditions is quite well documented as Karnes reported (Karnes, Schwedel, Lewis, Ratts, & Esry, 1981). Of concern are the vast numbers of these children born to single mothers who are from low socioeconomic communities and who are still in their early or mid-teens. Early studies of premature children and those with anoxia demonstrated that, except for the few babies with obvious disabilities, these children's early developmental delays were essentially washed out by 6 or 7 years of age...except, in most instances, for the children's low economic backgrounds.

However, in Hawaii where family financial status was not related to early comprehensive medical and educational service, it was the mother's education and IQ that were related to the child's later performance. Implications for the intervention needs of inner city and isolated children who are medically fragile or who have chronic health problems are strongly suggested.

SELECTIVE/RESPONSIVE STIMULATION

The objective of reduced hospital stays is to be applauded. But dehospitalization alone is probably not enough. While placement in a foster home or in the home of a nurse is acclaimed over hospitalization, one asks if the nurses in the foster home or other facility are prepared to provide the psychoeducational interventions appropriate for children with developmental delays, or for those who have established patterns of relative inactivity due to major health problems. It has become clear that stimulation *per se* is not the answer to fostering early development. Years ago, Cronbach (1969) decried the booming, confusing environments imposed upon children. More recently, Millar (1972), Lewis and Goldberg (1969), and Lewis and Coates (1980) have demonstrated that what is called co-concurrence, or caretaker's immediate response (within 2 to 4 seconds) to the infant's actions or vocalizations is significantly more effective than the provision of time delayed or unrelated sensory stimulation. Without those immediate reinforcing responses, specific skills may not be learned. For babies up to 3 months of age, proximal concurrence (cuddling, stroking, whispering) resulted in significant gains on infant scales; for children to 3 years, the distal responses (speaking, signaling) were the more effective (Brinker & Lewis, 1982). Sensitivity to these differences should dictate differential interactions between the young child and the adults with whom he or she relates. The provision of excellent medical care is essential for the medically fragile young child, but it is not sufficient.

J. McV. Hunt's recent work with young orphans in Teheran demonstrated that concentrated music and mother talk did not result in less retardation. However, when he provided systematic instruction through a systematic language oriented program, it resulted in performance superior to that of a control group in the Worchester area of Massachusetts.

It is also well known that babies can control their own stimulation and they can move their bodies in order to attain their goals. Lipsett at Brown University hooked up babies so that through their own movements (for example, kicking or sucking), they were able to activate a slide projector. Those infants continued to kick or suck harder and faster in order to elicit their chosen black and white highly contrasting pictures rather than the pastel ones which we, as adults, usually select for newborns.

The suggestion of programming for young children who are medically fragile requires that the primary caregiver or program coordinator be aware of the increasing body of knowledge and skills related to the facilitation of child development. In other words, especially for ill children, "love is not enough." Nor is infant stimulation always appropriate. Also, parents and other caregivers who are the primary programmers for their child will need help in developing skills specific to that child.

TEACHER COMPETENCE

Teachers who assume membership on the transdisciplinary team for children with medical problems need sensitivity to their own values--moral, ethical, and professional. They also need awareness of their views of life and their beliefs about the value of a child's activity as long as he or she is alive.

The teacher requires readily applicable knowledge of procedures to be followed at times of crisis such as insulin reactions, seizures, and asthmatic attacks. Probably of greater importance is the need to recognize behavior or physical changes suggestive of an impending crisis and of measures to be taken to avoid emergencies. Of benefit to the new or prospective teacher is a supervisor or cooperating teacher who has successful and active experience in hospital teaching and in membership on a medical team. In-depth knowledge of the roles of the team members and the professional language they use will facilitate planning and program implementation.

The factors influencing educational programming for medically fragile children are common across diagnostic categories as well as specific to unique conditions. Diagnoses do not reflect homogeneity of symptoms nor common constellations of special needs. The medical diagnosis provides little educationally relevant information. It is possible that the medical conditions' unpredictability is one of the common factors. However, teachers need to be alert to flare-ups, emergency precautions, diet, fatigue, physical restrictions, physical treatments and daily living procedures, reactions to medications or foreign substances, and to public reactions as in the case of AIDS or other transmissible problems.

Accompanying many of the above factors are probably the two most critical ones in the creation of an individual's body image: pain and motor control over one's limbs (Schilder, 1950). The role of pain in the reformation of the body image after illness or disability is not really understood as yet. Pain is subjective; no other person can accurately judge the intensity or impact of pain. Worthy of investigation is the apparent analgesic effect of activity and attention (White & Sweet, 1955).

PROFESSIONAL PERSONNEL

If medically fragile and chronically ill children are to be able to associate as peers with nonhandicapped children, and if they are to be included in the mainstream of education, school personnel knowledgeable about the unique needs of these children are required. It cannot be assumed that the presence of a counselor in a school will meet the needs of a teenager with muscular dystrophy or one with leukemia. The counselor whose major experience is related to college admissions is not usually prepared to meet the student's IEP specifications for guidance. Nor have most high school counselors had experience in assisting medically fragile students face their dying and/or their death; they are hardly skilled in facilitating heterosexual relationships of the youngster with spina bifida. Also, it is not unusual to find that other personnel, for example, school nurses, need assistance in accepting responsibility for medical procedures not usually part of a school nurse's job description.

A child who needs sterile catheterization, who requires suctioning of a tracheostomy, or is respirator dependent need not be deprived of attendance in a local school. Increasingly, community schools are available to medically fragile children who start their lives at risk. Since mobility, through technology and social action is being extended, it can be expected that most medically fragile children will be enrolled in regular classrooms at some times in their lives. For example, if travel/transportation is not counterindicated, it may be possible for even the most delicate child to attend school with nondisabled children or with others encountering forced restrictions or intrusive therapeutic interventions. It is now possible, with modified vehicles, to transport children on stretchers safely affixed to the vehicle floor, in complex adaptive wheelchairs, with respirators and with attendants to assure emergency care en route, if necessary. To guarantee safety of respirator-dependent children in school, emergency generators have been made available for use during power failures. It is this kind of positive and creative planning which is making the concept of least restrictive environment (LRE) a reality for children with serious health problems.

There is no doubt but that education for the low incidence medically fragile children can be very expensive. As the student moves toward the least restrictive environment from the hospital setting, to tutoring in his or her own home (or in a foster home), to actual attendance in a community school, the expense to the school for educational and related services including a modified environment, equipment (such as nebulizers, mist tents, mechanical percussors) and therapeutic services, transportation costs will mount. A strong case can be made that social crippling resulting from isolation could be more damaging than the physical risk or even loss due to reduction in the intensity of therapeutic intervention.

Among the most critical factors in establishing social, medical, and educational policy for the groups of children who are medically fragile or who have chronic health problems is their multifaceted heterogeneity, for example, in diagnosis, etiology, severity, multiplicity of disabilities, and in prognosis. Recognizing the difficulty of studying health problems in terms of social and psychological variables, Starfield (1985) has presented a profile which categorizes the outcomes of such illness along seven dimensions: longevity, activity, comfort, satisfaction, disease, achievement, and resiliency. Measuring the interaction of illness with each of these factors with instruments to determine what the child is experiencing could provide valuable guidance to both professionals and parents. At this time, however, programs must continue to be devised and revised on the basis of meager emerging empirical data as well as on clinical judgments and inference.

On that basis, it appears that these children often experience prolonged, lengthy and/or frequent but brief or episodic absences from school. The school's bridges from the classroom to instruction in the hospital, or to the child's home, seem at best frail and usually nonexistent. Piaget and others have suggested the importance of program continuity and sequence in facilitating learning. Yet, not all state and/or local education agencies have accepted responsibility for educating medically fragile children in public school buildings (Viadero, 1987).

MANAGEMENT

As indicated earlier, the majority of children who are medically fragile or who have chronic health problems can attend school with their peers. But, their school placement is dependent upon their educational rather than medical needs. Traditionally, in many urban centers, special schools or units were set aside for educationally heterogeneous groups of children on the basis of their having received a medical diagnosis of a physical or health problem. With changes in treatment and emphasis on providing education in the least restrictive environment possible, such facilities accommodated only those children with major functional impairments.

Among the barriers to normal school relationships are management problems and embarrassing factors, such as incontinence and catheterization, unpleasant odors and discolored teeth resulting from required medication, seizures, diabetic coma or insulin reactions, loss of hair due to chemotherapy, and facial or bodily deformities such as curvature of the spine, abnormal growth patterns, and the potential unavoidable emergencies which attract undue attention. Critical also are the attitudes of adults, including parents, teachers, and others with whom the child comes into regular contact. Some tend to be oversolicitous, overprotective and have lowered expectations; they might also be fearful of potential physical crises, possible contagion, and reactions to dietary modifications, school programming, special transportation needs, and home arrangements. The need for empirical data on the treatment effects and implications for practice are needed.

Data on the effects of such factors as anxieties about the illness and treatment on a child's learning and concentration would be helpful in educational planning. It is also evident that treatments can be exhausting, painful, restricting, helpless, stressful, frightening, and/or isolating. Returning to school after an absence or a number of absences can be confusing and frustrating for a student. It might be expected to reinforce a child's sense of inferiority and general low self-esteem.

Medically fragile students usually live with low stamina and energy levels. Thus, they are often denied opportunities to play or work with active and healthy children lest they "overdo" or are exposed to infections. Other impediments to child interaction relate to limited access to school areas because of architectural barriers, extensive walking distance, or exposure to undue environmental pollution or temperature changes. Not to be overlooked in educational planning are long term and intermittent school absences due to specialized treatment, periods of hospitalization, or confinement to home. It is at these times that educators must assure a continuity of programming. The creative teacher finds ways to prepare an individualized program which can be followed by the child and a teacher, or even a family member, so that a sense of continued participation can be realized and that, upon return to school, the child will not experience a lack of accomplishment or of feeling left out of school activities. Thus, a child's communication with the classroom teacher and information about classmates can foster a sense of continuity for the unavoidably absent child.

In addition to the psychosocial aspects of discontinuity, Lemkau (1981) has suggested that severe interference with stimulation, the balancing of stimulation, or insufficient stimulation during a critical developmental period can result in failure to develop functional integration. As a result,

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the child has less meaning to give to subsequent experience even though the brain has many functional connections. One need think only of the power of the pain, the fear, anxiety, and the isolation of hospitalization, the tests and/or the intrusive treatments to appreciate the potential disruptions of cognitive, emotional, and social development. The students' erroneous attribution of causality between being ill and unloved or having been "bad" are not easily understood by adults.

It is not unusual for parents to be confused. The uncertainty of the course of the illness, its being permanent or life threatening can lead to problematic expectations upon which questionable relationships and assigned responsibilities are based. Distracted and exhausted parents need help. They need support in adjusting to the situations and in providing the consistent predictable stimulation and life experiences from which the child can learn systematically with motivation and opportunity for practice and feedback.

Some of the questions to be asked by teachers as educational programs are being planned include:

1. Are there special emergency procedures or precautions for which the school must be prepared?

2. Does the child require a special diet? Are there foods which must be avoided? Is special preparation or consistency required?

3. Is the child required to take medication? Can it be administered by school personnel or by the child independently? What are the possible side effects of the medication? Does the medication cause, for example, anxiety, irritability, inattendance, drowsiness? Are there special symptoms which indicate immediate need for medication or for modification of dosage?

4. Are there safety precautions that must be taken, for example, use of a helmet, standing table, wheelchair or brace, limits on time for standing or walking, need for physical support?

5. Are specific programmatic arrangements necessary, for example, rest periods, restricted physical education, counterindicated physical activities, reduced school day, special seating, assistive toileting, special transportation?

6. To what extent is the child's health problem stabilized? Is it progressive, and if so, what changes can be expected? To what extent will environmental or programmatic changes be necessary? What is the projection for the future performance?

7. What related services such as speech/occupational or physical therapy or specialized counseling services does the child require? How can such program requirements be obtained and scheduled?

8. What is the child's understanding of the health problem and its implications? What is the parents' (family's) understanding of the child's problem? Does the child or the family require special training in order to increase independence in personal or physical management?

9. What kinds of counseling assistance do they need to clarify the situation and cope with it? Is there awareness of the course of the health problem, for example, are they prepared for physical deterioration and/or the death of the child?

Answers to these questions will provide the basis for meetings and planning of the several professionals with responsibility for the health, education, and welfare of the child and his or her family. It is urgently recommended that effective communication be established with parents as early as possible to enhance the family's ability to comprehend, to carry on roles, and to establish satisfying coping strategies.

Special attention is required when a child returns home from the hospital. It is natural that fear and anxiety will be mixed with joy and relief. All staff members will require support, openness, and sensitivity in providing brief but accurate information to parents as they assume control, restructure their living patterns as necessary, and reduce stress to the extent possible. Among the special educator's important skills is his or her ability to listen and to accept without personal offense, possible sudden outbursts of anger, "unfair" accusations and transfer of feelings of guilt and shame. Blackston highlighted these factors. He also called for recognition of personal feelings of helplessness and of being overwhelmed in face of a student's serious and devastating illness which is painful, progressive, and/or terminal. He also pointed to the need to reduce periods of hospitalization as well as to consider the parents' needs for respite care. To him, parents' pursuit of their own careers and normal life activities are critical to their mental health and to their effectiveness in dealing with the long-term intensive education and care of their child.

In conclusion, the above comments are supportive of Dr. Blackston's informative paper. Among the supplemental emphases presented for educators have been the following:

Severely handicapped infants need careful and systematic formal assessment. But probably more important are the systematic observations of the child's behaviors--his performance. Professionals can and do make errors; standardized tests have limitations, especially for the children under discussion.

Severely handicapped young children need clear program objectives, but teachers/professionals need to be ready to respond to the child, not just provide stimulation according to what adults feel are the needs. Definitive judgments about present ability or potential of the medically fragile child are difficult to make, and there are ways to circumvent, or even prevent, many of the multiple problems these young children face.

Technology, for example, will permit (1) better health, (2) better response to the environment, (3) more response from the environment, and (4) more movement. Above all, the educator cannot give up on the child as long as he or she lives. The determination of "terminal" illness may be reversed. The extent of life can seldom be predicted with accuracy! Neither physical nor psychological internment is justified as long as the child lives.

No one profession can assume full responsibility for the development of the young medically fragile child. Teachers must be prepared to assume roles which traditionally have not been theirs. They must also be released from some of the roles which have been recognized as theirs. Above all, they must continue to learn.

Direct and planned teaching is essential but babies' sounds and developmental movements must be reinforced immediately and encouraged.

Parents (primary caregivers) are the most important factors.

The teacher's primary task is the liberation of the learner, as suggested by Maritain (1943). That liberation for the medically fragile child requires his or her being encouraged to live and learn to the fullest.

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A RESPONSE

Barbara Sirvis

Dr. Blackston presented a refreshing and positive perspective on the care and treatment of students who are medically fragile. While many of his medical colleagues still seem to use a traditional medical model, he presents programs for returning students to their own schools as well as home-based support for students and their families. He is to be commended for his work as a team member with professionals from numerous disciplines including education. It would seem that his underlying philosophy highlights quality care, a factor that has numerous dimensions and specific concerns for special educators whose professional assignments call for work with these students whether they be in the hosptial or the school setting.

CROSS DISCIPLINARY SERVICES

The recognition that a "balanced approach" must be used in the delivery of quality services to students who are medically fragile emphasizes the need for continued recognition of issues related to quality of life. Although this phrase may be considered by some to be trite and overused, it has specific positive application in the intervention programs Blackston described: Reintegration of hospitalized children into their home communities, often with extensive support services. These support services facilitate the child's transition from a medical facility to his or her home and community. They decrease potential development of negative feelings and disruptions for parents and siblings, thereby enhancing potential development of a more normal family existence.

Blackston acknowledged the importance of educators in the process, noting that their task is often "difficult when...expected to understand the varied problems of the chronically disabled, fragile child..." He outlined several physical symptoms which may be overlooked or inadvertently attributed to underlying emotional problems; lack of acknowledgment of these physical and emotional problems may hamper a student's performance. Several emotional aspects may be "triggered" by events involved in treatment or in home care. These aspects have relevance for students as well as for their parents and teachers and other human service personnel involved in their care and treatment. Connor identified and elaborated on several physical, social, and emotional aspects that may impact development of the student who is medically fragile. While she and Blackston both presented substantial support for transdisciplinary intervention, the philosophical issue of quality and quantity of life has yet to be addressed. It seems imperative that this aspect of life per se be acknowledged and addressed specifically with reference to this particular group of students and for the professionals who will work with them and their parents.

QUALITY OF LIFE

As modern medical technology has increased the potential lifespan for students who are medically fragile, discussion has begun on the quality of life and the development of programs that encourage student, teacher, and parental examination of issues related to quality of life. Among these potent issues are the importance of humor, leisure education, behavioral expectations for participation in family life, and death education. All of these are important life issues which provide focus for discussion and recognition of the importance of each day and all aspects of human interaction to the quality of the lives of students and their families. Death education provides a forum for discussion of these important topics and others that provide life-centered focus.

Traditionally, death and dying are thought of as an issue to be faced by personnel in medical situations. However, increasingly, education and other personnel need preparation to deal with death. Beginning with introduction of the life cycle of plants and animals, students can be aware of the natural life cycle of all living things; this information begins their understanding. While chldren do not usually begin to understand the permanence and finality of death until the preteen years, they understand loss from an early age. Introduction of the topic establishes the place of death in life and it appears to create an atmosphere conducive to discussion rather than closing their options to discuss this often difficult and emotional topic.

The death of a peer is difficult for students, and often for their teachers, to discuss. Teachers and prospective teachers are in need of opportunities to examine their own attitudes and be prepared to discuss the topic openly and honestly. While they may be uncomfortable, it is clear that lack of conversation and expression of sentiment puts death in the non-discussable category, potentially creating early and long-lasting difficulties with their development of coping skills essential when death becomes a critical experience for their students.

Numerous resources exist for teachers to use in the examination of their own attitudes and of their roles related to death education as well as for their use in introducing the topic to their students. The short bibliography at the end of this response can be helpful to teachers seeking content for materials to incorporate in lessons that introduce the topic prior to the time that students may have to deal with death. Death education content can be incorporated into existing curricula; it need not be developed as separate lessons. For example, "story-time" can include an age-appropriate story dealing with death, and science can present the natural life cycle of all living things.

Teachers require preparation for talking with parents regarding death education. Parents needing assistance in establishing their own comfort level with the topic, or even in realization that they must deal with the potential early death of their child are increasingly turning to teachers for guidance. The family needs to be encouraged to continue an "active living" approach with their members, with realization that focus on the concept of "living in the moment" is usually more productive than concentration on the future only.

The foundation for creative, positive intervention programs such as those discussed by Blackston is recognition of the importance of quality of life for all individuals, regardless of projected lifespan. Teachers need to find or work toward initiating similar programs in their communities as well as develop curricula which foster student discussion of related topics. In addition, they need to be ready to discuss these issues with parents. Clearly, students who are medically fragile present unique needs for educational intervention. However, the underlying philosophy in program development should be recognition of the importance of creating an atmosphere which is conducive to support of the high quality of life possible for the child and his or her family.

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ACTION AGENDA TO IMPROVE THE EDUCATION OF LOW INCIDENCE HANDICAPPED CHILDREN

Frederick J. Weintraub

As the post right-to-education generation begins, special educators should take pride in what has been achieved in recent decades. However, the mission for the future is not merely the implementation of the past, for on the whole that dream has been achieved. The next era calls for developing and following a new vision for exceptional children and youth--vision forged on their future needs and tempered by the knowledge gained from the past. It is, therefore, incumbent upon special educators to set the agenda for the future and to advocate for its achievement.

In developing an action agenda for the future, four influential themes appear to emerge as critical in shaping such an agenda:

LIFELONG OPPORTUNITIES

Exceptional persons need to be assured of access to a lifelong continuum of appropriate educational opportunities. While there are many facets to such a continuum, several issues require careful consideration.

Significant efforts need to be undertaken to ensure early intervention and preschool services to all exceptional children who require such services. Numerous state, provincial, and local efforts, buttressed by the new U.S. federal initiatives set forth in P.L. 99-457, represent major steps forward on this agenda, but much more remains to be accomplished. Special educators must support and advance critical roles that family and community play in a child's development; also, there is need to provide the professional developmental services the child requires. Clearly, special educators will need to learn how to function as an integral part of a multidisciplinary team since instruction is only part of the complex of developmental services required by very young children and their families. Continuity and consistency of services, curriculum, and methodologies for these children and families as they move across various service systems and professions are another critical issue requiring careful attention.

Exceptional persons do not cease being exceptional learners upon graduation from high school. They need assurance that all systems providing for lifelong learning opportunities will be designed to accommodate their unique learning needs. Special education has come to recognize that, for the most part, it does not cure exceptionality and that most of its former students will continue to require some adaptations as adults in order to enhance their acquisition of new knowledge and skills. In an expanding "information society," being a lifelong learner will be a critical attribute for personal success. It is time to integrate the special education profession into the varying delivery systems of lifelong learning to ensure that the unique learning needs of exceptional persons are met.

There is growing concern about improving the ability of exceptional individuals to transfer from school into the varying aspects of adult life. While this move is fraught with important unresolved issues, it is recognized that transition is a lifelong process and not a single event. Transitions occur at numerous points during the school years and throughout one's remaining life. A major goal, then, of special education is to prepare students and families with the knowledge and skills necessary to deal with transitions and to provide the counseling and support needed to smooth such transitions.

IMPORTANCE OF THE INDIVIDUAL

Special educators need to ensure that decisions about services to exceptional persons are made on an individual basis. If there is a basic tenet of special education, it is that children differ in what they need to learn and how they learn. Further, delineations assigned to children, such as varying exceptionalities, grade levels, or test scores should not frame the base for decision making regarding a child's appropriate education. Just as the commitment to individualization precludes acceptance of a single educational curriculum, teaching method, or environment for all children, so, too, is it inappropriate to suggest the possibility of a single educational curriculum, teaching method, or environment for all children who are deaf, who are blind, or who belong to any other designated group. If the differentiated needs of exceptional children are to be met in the future, there is need for better determination of what the unique learning needs of an individual child are and of ensuring the available quality alternatives to meet those needs. Rather than continuing to use special education placement as the primary mode of individualization for exceptional children, new means will be developed in order to build appropriate programs to account for the complex situations presented by low incidence populations. In the future, less time should be spent debating environments while more intensive efforts should be focused on the curricular, methodological, and service needs of the child and how such needs can be met best. In this context, there is obvious need to expand the base to be considered in examining a child's needs to include factors related to social and cultural development, the needs of the child's family, and health and safety of the child and others with whom the child will associate.

QUALITY OF EDUCATION

The most critical challenge facing special educators is the continuing improvement of the quality of the education exceptional children receive.

During the past two decades, attention has been focused on access and process; however, while these components are important for the future, it is clear that they alone do not assure a quality education. It is through the ongoing efforts of well-prepared personnel with adequate resources and appropriate working conditions that exceptional children will receive the quality education they need. In this regard, there are four components which should shape our action agenda for the future: qualified personnel, adequate resources and working environments, high standards and control of practica, and research to enhance the body of knowledge.

New efforts are required in order to develop and maintain a sufficient cadre of qualified personnel to provide for the education of all exceptional children. To achieve this end, demographic, economic, and political realities suggest a number of steps to be taken. First, new approaches to differentiated staffing systems should be developed to maximize the effective use of highly trained, capable professionals. Aggressive campaigns to recruit talented young people and persons from other walks of life into careers in special education are critically needed. Professionally recognized standards for preparing special education personnel must be promulgated and enforced and only persons who meet professionally recognized standards should be permitted to practice the profession. Given that the knowledge base in the field is ever-expanding and improving, special education professionals should be able individually to establish and pursue, with support, their own continuing professional education. If, as a profession, special education is to be accountable for the continuing improvement of the quality of its instruction, then as professionals, special educators must have control over who is considered qualified to practice the profession.

Without assurance that professionals working with exceptional children have the resources and working conditions, effective practice is unlikely. In this regard, the profession should determine appropriate case loads and class sizes and work to ensure that standards are maintained. It is important that professionally established standards of practice be recognized by schools and other service providers and that professionals employed by such agencies be assured the right to practice in a manner consistent with such standards. Finally, professionals need assurance that they will have available to them the environmental conditions and professional resources (e.g., instructional materials, technology) necessary for effective practice.

Quality in any endeavor, including special education, is an elusive goal since new knowledge makes it ever-changing. For this reason there is need for effective systems for the development of new knowledge and the linkage of that knowledge to practicing professionals. Research must then be considered as an integral component of the special education structure with assurance that there are adequate resources for its support. But if such research is to be valuable, it must be conducted under conditions comparable to those in which professionals practice, and systems must exist through which the new knowledge can be translated from such research into the resources and techniques professionals need for improved practice.

Greater attention needs to be given to improving and managing curriculum in several aspects. First, it is expected that many exceptional children will grow up to be exceptional adults. To the extent possible, they need to understand exceptionality and learn how to live in society as active and respected members. Second, for exceptional children who cannot complete the core curriculum of education, alternative curricula relevant to each child's ability must be generated and systematically designed for individual students. Finally, for exceptional children who can be expected to complete a basic education core curriculum, but who also require special educational assistance, better management of learning will be necessary to ensure that the children actually complete the curriculum and can demonstrate the skills requisite for productive citizenship. Continual effort is called for in order to improve the content, organization, and instructional methodologies used in the education of the variety of exceptional children requiring special education. In this regard, there is need for precise information about what works, with what children, and under what conditions.

New technologies offer many opportunities and challenges. Through adaptive technological applications, it will be possible to compensate for some unique functional barriers and learning deficits that the children display. Technology can facilitate learning and performance. As teaching tools, new technology will open great opportunities for special educators to access curricular options, use multiple methodologies, and provide guided instruction and encourage opportunities for independent learning. However, such technologies will be useful only to the degree to which special educators commit themselves to learning how to use them effectively.

In the future, efforts will be made to ensure that special education resources, policy, and administration are appropriate to the provision of quality special education. Periodic review will be essential to ensure that these factors enhance rather than impede the effective delivery of quality instruction. There must be a clear articulation that the purpose of special education is to provide quality instruction and the conviction that resources will be utilized to maximize the achievement of that end. Policies, procedures, and administrative structures that appear to be ineffective should be reexamined.

WORKING IN A COMMON CAUSE

Strength to meet the future's challenges lies in knowledge gained in meeting those of the past.

Professional special educators must have a wholistic view of the field. We must remain advocates for all exceptionalities and all members of the profession. It is not productive to play one interest against the other, even for the "good of the student." Nor is it appropriate to promote concepts that some children's needs are greater than others or that some interests care more than others. While diversity of view within the profession and the larger community of concern has always been a strength of the field and should be encouraged, the powerful debates are most potent when the contenders speak with evident mutuality of respect.

Achievements of the past to a large measure were a result of parents and professionals working together in a common cause. Maintenance of that capacity mandates continued diligence. Finally, the challenges of the future will require advocacy on the part of each of us and all of us collectively. Bringing that advocacy to all situations where it is needed calls for a strong commitment of self and resources to the organizations that represent us and a willingness to contribute personal time and direct action when necessary.

Together CEC members have attained many of the dreams of the past; together it is possible to dream again and to build a brighter future for exceptional people.

A RESPONSE

June Mullins

Fred Weintraub has provided a broad and provocative view of the education of the low incidence population of physically and sensorially disabled children. This reaction is a counterpoint to his creative and divergent thinking, offering a more convergent approach. An effort will be made to define the limits of educational responsibility that should be assumed by special education teachers, particularly with respect to medically fragile students, the subcategory of physically and sensorially handicapped students that has been under consideration in this symposium.

PROBLEMS CONFRONTED BY TEACHERS

As emphasized by other speakers and discussants, teachers are confronted with a number of extraordinary problems when their students include medically fragile children.

Family Problems

When students live at home, teachers will, perforce, develop close relationships with parents and caretakers, particularly when the teacher provides instruction in the home setting with very young children. It may become difficult for the sensitive teacher to avoid becoming emotionally involved in the family's feelings and reactions relating to their handicapped child and even in other parts of the parents' lives.

The family's economic problems are often overwhelming, especially if they lack medical insurance--an increasing probability in these times of high unemployment. The extraordinary initial, and often ongoing, medical expenses incurred for these children may have a catastrophic effect, even in families at an otherwise comfortable economic level. Families seeking solutions have resorted to bankruptcy, sacrificed savings, and/or borrowed heavily to pay medical bills.

Teen-age pregnancy, drug and alcohol abuse, and history of child neglect and abuse tend to be overrepresented among parents of severely disabled children, leading to parental feelings of guilt, defeat, and depression. It is not surprising that special educators, in addition to facing educational dilemmas, at times feel overwhelmed by these circumstances as well.

Medically Related Problems

Teachers of medically fragile children are required to function on an interdisciplinary team where medical exigencies, dictated by non-educators, must often take precedence over the educational needs of the student. The medical goals of the IEP, mandated by the child's physical needs, may demand such time-consuming procedures that the pursuit of more educational goals could seem impossible or irrelevant.

Teachers frequently express their fears about witnessing the death of a student, or about inadvertently acting in a manner harmful to the child. Not to be overlooked are the often expressed fears of consequent legal liabilities (although their coverage should have been arranged long before the acceptance of a teaching assignment).

Medical practices may not be consistent with the best psychological or educational practice, especially from the perspective of an educator. For example, at present, in one large city hospital, a wing has been constructed to provide long-term residential care facilities for low birth weight, high risk infants. Such a facility, rather than a home with necessary medical resources, is not optimal for infant development, nor is a hospital the least restrictive environment for most older children.

Further, special educators of severely disabled children are often witness to and participate in painful procedures and extraordinary medical interventions, necessitated to preserve the lives of their students. These experiences may be very worrisome to teachers, parents, and to the young patients themselves.

Finally, teachers may be ambivalent and frustrated over their students' serious health problems which are so recalcitrant to treatment. Notable are the TORCH diseases and AIDS (highly damaging, with some easily transmitted), and such life-threatening genetic diseases as muscular dystrophy and sickle cell anemia.

Resource Priorities

Medical and rehabilitation practices with ill and severely handicapped children are not always dictated by what is best for the child; rather, the roles of economic exigencies and politics in decision making are sometimes uppermost. It is not unusual, for example, for the quality of educational and rehabilitation intervention to be a function of the presence, or absence, of third party payments. Tens of thousands of dollars may be expended for a transplant, or home respirator care, or dialysis for one child, while at the same time many other children do not receive the most basic medical or nutritional needs. Treatment inequities have resulted from regional and socioeconomic inconsistencies and differences. For example, State Supreme Court decisions have differed markedly from state to state regarding the provision of supportive services in facilities such as the community school, private school placement, or in a clinical setting.

Finally, educational personnel may experience pressure from the school districts to provide noneducational medical techniques such as suctioning, administration of respiration, feeding and positioning, and Crede'ing simply because of the expense involved in employing experienced personnel to administer to students. Ideally, decisions on such matters should be decided case by case, on the basis of the most appropriate educational environment for the student, with the consultation of medical specialists. Included in such decisions is consideration of the teacher's need for supportive services. In some instances, administrative and economic considerations are given the higher priority.

The Extraordinary Problems Confronting the Students

Special educators need to be alert to possible discouragement as a result of the limited amount they can do for their sick and very disabled students. They may helplessly witness children's suffering, physically or psychologically, daily. They will visit children who are being physically "maintained"; those who will not improve medically, and some who deteriorate and die. Fortunately, when working as part of a sensitive and competent team, these teachers will usually be sustained and heartened from time to time by children who are "medical miracles," educational successes, or just delightful and responsive human beings.

Teacher Burnout

All of the problems and difficulties mentioned above threaten to overwhelm sensitive and conscientious teachers. There is need for study of the factors critical to teacher satisfaction and vitality; school leadership personnel need to be available for staff showing signs of feelings of potential futility, inadequacy, or guilt. Also, attention is required for those who might become cynical or callous.

DEVELOPMENT OF A PHILOSOPHY OF ADVOCACY

Personal Advocacy

Given stark realities about what teachers as individuals can do and must do, how can they protect themselves spiritually and psychologically, and still work optimally for the students in their charge? What preparation is available for new teachers who have chosen to work with the medically fragile populations under discussion, or even for seasoned teachers who are encountering children's complex disabilities for the first time? The proposal being suggested here is the separation of professional advocacy from personal advocacy.

The latter, personal advocacy, deals with one's own views: religious, political, and idiosyncratic. These views may be strongly held opinions about such issues as the right to life, the proper limits of medical intervention, the allotment of financial responsibility for expensive educational placements and services, and the justice of existing political and legal practices.

As citizens, special educators need to pay serious attention to these issues. As citizens, we have vehicles through which we express opinions to resolve such issues--our votes, our professional organizations, churches, and the like.

Professional Advocacy

It seems that for special educators in the front lines serving medically fragile children and working with their parents, issues such as the above are not an individual's professional concern. A realization of this concept could relieve teachers from some of the feelings of anxiety, tension, powerlessness, and despair that have been mentioned so often in this conference.

Educational Propositions

What can special educators advocate with certainty, regardless of the opinions and practices of those who share responsibilities for medically fragile children?

Research, and often experience, have supported certain educational propositions that can guide teachers.

For example, all children can learn, and learning begins at birth (if not before). Further, this learning must be facilitated from birth, even for the most disabled or immature infant, in order for the child to develop optimally. There is also evidence that in the categories labeled as physical or sensory handicap, there are a number of individuals with normal or high intellectual potential who are eager, though physically fragile, students.

Also, it is unreasonable to expect medical and rehabilitation staff, who are not trained in instruction, to act in the capacity of teachers, or to be responsible for the psychological/cognitive development of the medically fragile patient with whose physical care they are entrusted.

From long experience, special educators of medically fragile children know that many, if not most, parents of extremely atypical children are unable to nurture their preschool exceptional child maximally without intervention from educational specialists. Of major importance is the parent involvement and support addressed in the early childhood education mandates in the amendments to P.L. 94-142 and its amendments through P.L. 99-457.

Research supports severely and multiply disabled children's need for year-long educational interventions if they are to maintain gains. The continuation of such services throughout the developmental stages of life into adulthood is needed.

Lastly, special educators possess bodies of knowledge peculiar to education of children in each of the traditional categories of exceptionality. When confronted with the challenge of medically fragile students, they can apply specialized skills in an appropriate manner; they know what support they and their students must have in order to maximize that student's educational potential.

Limits of Educational Responsibility

Educators are justified in assuming a strong advocacy role with regard to the above propositions as they work with other professionals including nurses and physicians, as well as politicians and administrators who make decisions about their students.

The next points may seem negative since they deal with what cannot be expected of teachers and of the educational environment. The classroom and educational services are not an extension of the hospital, nor of the home, nor a baby sitting service. Parenthetically, controversy has arisen during this conference about the educability of so called brain dead and comatose youngsters, surely a very small population. It still seems appropriate to hold to the premise that all children can learn; a chance can be taken with those few possibly permanently nonresponsive youngsters.

Finally, the school system should not have to bear the total financial cost resulting from social and medical decisions. Rather, the system should pay for excellent education that special educators will provide to the best of their ability, wherever and whenever, to all disabled children.

Conclusion

In conclusion, then, special educators can become the most effective advocates for their students, and function optimally on the educational and rehabilitation team when they act from the perspective of their profession. They need to be explicit about what education means and what it does not mean, what disabled children need that special education can provide, and what teachers need to do the job.

A RESPONSE

Anne L. Corn

What Fred Weintraub has said is certainly relevant to all who face the challenges of educating children with low incidence handicapping conditions. However, the topic of advocacy will be approached here from the perspective of an educator of blind and low vision children.

To a representative of the lowest of the low prevalence handicapping conditions (approximately .1% of the general population), and often one which is seen as a highly specialized area, it is obvious that the Weintraub statements must not be taken lightly. This is a critical time for renewed effort to ensure that these students are currently receiving and will continue to receive an appropriate education in their least restrictive learning environments.

There are three interrelated areas to which the following comments are addressed: teacher certification, service delivery, and curriculum for students with a visual or other handicap which falls into the low incidence grouping.

If we accept the premise that generically prepared teachers will not have the competencies required to serve children who have visual handicaps, for example, to teach braille, understand cognitive and conceptual development, teach the use of optical aids and orientation skills, then it follows that each child with a visual handicap requires a teacher with unique preparation in order to receive an individualized appropriate education. At present there is an extreme shortage of qualified teachers for visually handicapped learners.

Over the years, teacher vacancies have generally been expected in rural and sparsely populated areas; now, however, those shortages are evident in medium and large cities, even in localities where teacher education programs for the visually handicapped are well established. Parents are concerned. It is not unusual to find them phoning teacher education programs to find and entice qualified teachers to come to their specific areas of the country. Although the laws and judicial mandates are in place, without certified teachers, an appropriate education in a least restrictive environment is not universally available. Preparation programs for teachers of the visually handicapped exist in fewer than half of the states; thus teachers seeking disability-specific information must make financial and personal sacrifices to attend classes (often beyond those expected of other special educators). Through outreach programs, some colleges have been able to send faculty to rural areas to accommodate teachers' specialized needs.

Business approaches to staff development may translate into "grow your own teachers." Those who are advanced within certain companies are sent to school on company time while receiving their full salaries. An exceptional regular classroom teacher may be "advanced" by being sent to school for extra training. Models for personnel recruitment are available in the military services; for example, the medical education provided to enlisted physicians is repaid through a specific number of years of employment in the service.

TEACHERS

Concern that generic educators will be hired to work with low incidence students is already becoming a reality. School districts desperate for teachers with a special education background are hiring those with even minimal preparation in the field and hoping they will return to school for certification. Since fewer than half of the states have at least one program to prepare teachers of the visually handicapped, and since educators are often unable to travel such distances, increasing the teacher's knowledge is the district's responsibility.

Nor can the field be satisfied with teachers prepared as specialists 10 or 20 years ago. Once a teacher has received state and/or professional certification, there is no justification for an assumption of interminable excellence. Educational systems need to recognize the teacher's requirements for continuing education. In the last few years, great advances have been made in methodology and technology for visually handicapped students. Yet, most teachers of these children cannot update their skills at local colleges. Because there are so few educators of blind children in some geographical areas, linkages to other professionals and to resources are paramount. It is not unusual for some residential schools to be taking leadership roles in providing statewide services, that is, their work extends far beyond that provided on their campuses.

Now may be the time for an intensive national publicity effort about this challenging profession. But how? A letter seeking help from "Dear Abby," a newspaper column with huge readership, did not result in publication. Special educators need to explore, in a businesslike manner, the marketing possibilities for their profession. No longer can it be expected that special education teachers will automatically show up at colleges. Therefore, leadership personnel will need to learn new information and dissemination skills. Unlike most college faculties, teacher-educators for low incidence handicapping conditions require effective recruitment and marketing competencies. The services of professional recruiters, as businesses have, would help the field of special education.

"There is a need to ensure access to a lifelong continuum of appropriate educational opportunities." It is clear that such a mandate cannot be separated from teacher education.

EDUCATION OF YOUNG CHILDREN

In the low incidence areas, a definite need exists for programs serving children in the birth-5 year age range. Without such programs cumulative effects of disabilities occur. For example, visually handicapped children fall further behind in such areas as concept development and orientation skills.

There is a need for teachers with preparation and experience with both visual handicaps and early childhood education. Certification in combined teacher preparation programs is a must for appropriate services to occur. Parents have a right to know the backgrounds of teachers and the professional standards required for preschool services. Parents, as well as the children, are consumers of these services; are they receiving an appropriate consumer education?

Since early intervention is a major problem facing educators of visually handicapped children, the overall teacher shortage in this area becomes an even more emotionally charged problem. Families with blind or low vision babies are finding it almost impossible to obtain services of an educator who knows about blind infants. Yet, parents need to learn how to help their babies feel comfortable in the object world, feel free to move about through space, and begin to develop self care and socialization skills. Parents generally expect to communicate with their babies through eye contact; they rejoice when motor milestones are reached, and they dream about the children and adults their babies will become. It is clear that the education of these children and their parents needs to begin at the time of diagnosis. Without such programs, cumulative effects of disability will occur. However, will qualified teachers be available to provide that education?

CURRICULUM CONSIDERATIONS

As Weintraub stated, children with special needs in school do not cease to become special needs learners when they leave the educational setting. While focus is on starting children with early educational experiences, continuing learning needs cannot be ignored. Although individuals will have lifelong needs, education for all children must start with the premise that they have potential for becoming responsible citizens.

Special educators tend to "work themselves out of jobs" as their students gradually assume responsibility for themselves; an IEP which does not include independence oriented skills is not providing an appropriate education. Consider the Game of Independence: events, rituals, and tasks related to growing up with a disability are on the gameboard. At each spot along the board, children are learning something about having a disability.

It would seem that a curriculum should accommodate growing up with a disability as an essential part of an education designed for handicapped youngsters. With appropriate preparation, many students who have disabilities will find easier transitions into adult life and more options regarding employment and lifestyle. Among the topics to be included are: developing a locus of control and responsible behaviors, understanding events and rituals of handicapping conditions, support systems, problem solving disability-specific challenges, and societal approaches to disabilities including legal information and consumerism. Students need to learn about making their own decisions; they cannot rely solely upon the directives provided by teachers and other adults.

SERVICE DELIVERY

Advances in technology increase visually handicapped students' access to learning and to future career options. For those with additional handicapping conditions, technology and curriculum require individualized adaptations but offer promise for reaching functional levels and communication avenues not envisioned as possible a decade ago. These advances also present financial and staff development challenges to school systems, making accommodatives on low vision clinical exams for those who could read regular print with optical aids, or providing accessible software for those who cannot see computer screens are two examples of ways in which school systems can expand opportunities for education. But, new technology is expensive. How will schools assure students with low prevalence conditions that they, too, have a right to participate fully in the educational system?

While trying to deal with today's ever present problems, special educators cannot afford to lose this time without planning for tomorrow. The world is changing, and the curriculum being planned today for nondisabled youngsters will also have a profound impact on the education and life options of disabled students. A baby born today would receive educational services if the state or local school district has the necessary laws and qualified teachers available. In the year 2007 that child will be entering adulthood, perhaps ininto a world barely within present dreams. Society may be under the sea and, more likely, out in space. Will educators be prepared to know how the baby with a low incidence handicapping condition will fit into society? If today's 10-year-old blind child expresses a desire to work in a space factory along with sighted classmates, will the available education prepare him or her for such an option? Now is the time for a segment of our professional community to think and plan for the future to ensure equal access to society in the years to come.

Weintraub further stated that the most critical issue is to improve the quality of the education exceptional children receive. For the public day schools, it is time to examine the service delivery models of the last two decades in order to determine the extent to which their roles require adaptation to meet today's needs. It is possible that the present concepts of the continuum of services may no longer apply or be the most efficient for the 1980's. For example, the consultative or itinerant teacher making brief visits to a school for one or more days during the week may be outdated. One service which has been proposed by educators recommends that residential schools or state departments of education, based in conveniently located cities within a state, would hire qualified personnel for a new form of service. These professionals, based at the school or state level, will work with a child, family, school, and community for several days at a time, return to home base and be available by phone. This arrangement would be repeated at intervals which are appropriate for the individual child, for example, once every few months. Granted, a new breed of educator will be needed, one whose personal life may be enhanced by this type of professional traveling.

In one region of Texas where two itinerant teachers served 45 visually handicapped children in a 25,000 square mile area, there was difficulty in retaining teachers. The University of Texas sent advanced doctoral students and faculty to this area for two semesters and the Texas Education Agency assisted with funding. Some of the participants within the region traveled farther than did the university faculty; most participants designated Friday mornings for travel and they began classes at 1 p.m. This type of program, pioneered by such programs as Texas Tech University, are now ongoing. Texas' need cannot as yet be met. However, it is recommended that states experiment with approaches which might work for them. The value of personally selecting each future teacher of the visually handicapped and ensuring his or her commitment to living in the region is deemed to be feasible.

Research on service delivery systems is necessary. There is still need to determine the elements of an effective teacher education program as opposed to a watered-down compromise or decision based upon fiscal expediency. CEC's Division for the Visually Handicapped has recently developed and adopted a series of position papers on the education of visually handicapped children. The content of these documents may be added to the legal and ethical arguments which parents and educators use to assure visually handicapped children an appropriate education.

If asked to provide an action plan for the next few years which would educate children with low incidence handicapping conditions, I would say that first, the teachers need to be recruited, prepared, and available. Next, the delivery of services needs to be rethought so instruction is provided in the child's least restrictive learning environment. Thus, both residential schools and public day schools will need to cooperate in new ways. Also, a curriculum which will address both the common core of knowledge and disability-specific needs should be developed and applied.

This symposium has allowed all of its participants to examine many issues. Most of them are faced by teachers today; some will be future issues. If such problems and concerns can be brought to the attention of those in positions to effect change in the schools, this conference will have met its goals.

IMPACT OF TECHNOLOGY ON VISUALLY IMPAIRED CHILDREN AND YOUTH

Lawrence A. Scadden

This paper was adapted from a chapter entitled, "Implications of the Research and Development of Modern Technology on the Education of Blind and Visually Handicapped Students," by Lawrence A. Scadden, to be published in *The Handbook of Special Education: Research and Practice* (Vol. 1-3). Wang, M. C., Reynolds, M. C. & Walberg, H. J. (Eds.). Oxford, England: Pergamon Press.

Technology is affecting modern society as people seek time- and effort-saving means to perform common daily functions. The impact of technology can be seen in education, employment, recreation, and household activities. Eventually, no single group may benefit from the proliferation of technology in modern society more than will that comprising people who are blind or visually impaired. Consideration of the two areas in daily life that are most adversely affected by restricted vision--namely independent, safe travel and access to printed information--should provide the basis for supporting this hypothesis.

The information normally used by sighted individuals for accomplishing the tasks associated with these endeavors is typically obtained visually. The sighted pedestrian uses visual information for the identification of familiar landmarks that serve for orientation to the environment and for detection of obstacles, stairs, and other changes in the traveled surface that may prove to be hazardous. Similarly, information presented on printed pages, dials, and meters on home and work instruments and appliances, and that presented on cathode ray tube and video projection screens, can typically be discriminated solely through the use of vision. The inability to access these multitudinous visual media can severely restrict the independence and the educational and employment opportunities of those individuals living with visual impairments. Thus, blindness and visual impairment will become a handicap for those people seeking educational and employment opportunities within the environments that emphasize independent access to and manipulation of visually presented information.

Sensory aid technology can significantly reduce the effects of visual impairment by providing the user with information regarding the environment and objects contained within it, information normally obtained visually. Sensory aids are devices that either increase the usability of information presented to a sensory system--sensory enhancement--or present information customarily associated with one sensory modality through another intact systen--sensory substitution. Common examples of sensory enhancement aids are spectacles, magnifying lenses, and closed-circuit television magnifiers that enhance the usability of visual information by providing increased magnification, illumination, and/or contrast. Sensory substitution aids include canes, braille, tape recorders, and high technology devices such as the Optacon. In each case, information typically obtained visually is presented and secured through another modality.

Sensory aids are used to improve functioning for blind and visually impaired individuals in both of the areas of daily living affected by decreased visual ability--namely travel and access to printed information.

Technology exists that assists users in obtaining information about the presence of obstacles in a pathway, the spatial layout of one's environment, the output of a calculator or measurement tool, or the contents of an alphanumeric display.

The curricula in special education programs serving blind and visually handicapped students should include training in orientation and mobility, independent living skills, and the more traditional academic disciplines that emphasize literacy and computational skills. The vast majority of modern technological devices that can positively contribute to the education of blind and visually handicapped students relates to these latter literacy and computational needs. Thus, emphasis in this presentation is on devices that address these educational needs. Special attention will be given to computers and computer-access technology.

The computer is being used increasingly on all levels of education. Ashcroft (1984) quoted Senese of the Government Printing Office as saying, "Today we no longer ask, 'Will computers be used in schools?' We know they are and that they are being purchased by schools faster than we can keep count. Indeed, surveys of computers in schools are outdated by the time they are published." The microcomputer is operated by manipulating electrical signals, digitized information which can be presented by a video display terminal (VDT), voice synthesizer, or braille display. Today, with students commonly interacting with information contained electronically within the domain of a computer, the blind and visually impaired student could have equal and independent access to the vast majority of these educational activities if appropriate sensory aid access technology and training were provided. On the other hand, without these concessions, the longstanding gap between sighted and visually impaired students may actually be increased.

STATE-OF-THE-ART

Technology is advancing at an uneven rate in the different areas of application. Sensory aids, for example, are beginning to have a significant impact upon many people's activities of daily living. Instruments with speech output--such as calculators, clocks, and scales--are already widely accepted. The introduction of these tools into special education practice related to activities of daily living should significantly improve the independence of blind and visually impaired students as they advance into adulthood.

In orientation and mobility activities, on the other hand, technological aids have not yet advanced beyond the long-cane or dog-guide for most blind travelers. Although a number of technological travel aids have been developed and tested, few blind people have found these devices to provide a significant enough increment of improved travel performance to warrant their regular use. Some new products, however, hold promise of providing early assistance in the training of blind children. In the relatively near future, technology may be used to increase the rate at which young blind and visually impaired infants and young children learn spatial concepts that will in turn improve other orientation and mobility activities.

Access to information is the area in the daily lives of blind and visually impaired people that should be most affected by technology in the immediate future. Technological products designed to provide independent access to information are appearing in the marketplace. Use of these products should lead to increased educational opportunities for blind and visually impaired students studying in a computer age.

Computer access technology. The class of sensory aid technology used by blind and visually impaired individuals to access computers has been termed "access technology." According to Ashcroft (1984), access technology is defined as "the equipment, equipment interfacing, software, and instruction and instructional materials enabling independent use of microcomputers by visually impaired students." This technology may provide the computer user with tactile, auditory, or enlarged visual displays.

Although more thorough discussion of these display systems can be found elsewhere (Scadden, 1982-1983); Ruconich, 1984), a brief overview here is warranted. Tactile display devices comprise three types: the Optacon, paper braille embossers, and paperless braille display devices. Auditory display access technology typically utilizes speech synthesizers to present the material normally displayed on the screen. And, large-character display devices use either hardware or software systems to magnify visual characters to a size discernible by visually impaired computer users. In all cases, the user must have sufficient control over the informational display to provide flexibility in repeated review of the material and for detecting and moving the "writing cursor" or "pointer" on the screen. With appropriate matching of user and display technology, the computer user who is visually impaired can perform most computer-based tasks with a high degree of facility.

SENSORY AID TECHNOLOGY IN THE EDUCATION CURRICULA

Electronic technology has been steadily increasing in its use and its effectiveness within the regular classroom. Longstanding utilization of audiovisual equipment was supplemented by the electronic calculator and then by the microcomputer. Although computer aided instruction (CAI) has been around the educational arena for over 20 years, it was the introduction of the microcomputer in the past decade that began to revolutionize traditional educational processes through augmentation with technology. As indicated earlier, the vast majority of school districts in this country have some microcomputers for use by students, and the number is growing rapidly (Ashcroft, 1984).

Among the traditional educational uses of computers, Sanford (1984) included the following: computer-aided instruction, information storage and management, and computer-managed instruction. The author also presented some innovative reasons for using computers within educational settings such as: individualization of instruction, instant and nonjudgmental feedback, enhanced normalization, motivation and reinforcement, and self-paced repetitive drill and practice.

Each of Sanford's reasons for the expanding use of computer technology in education appears to be valid for all students--disabled and nondisabled alike--but they are perhaps particularly pertinent in the education of blind and visually handicapped students. As Kessler (1984) pointed out, in addition to meeting a legal obligation to these students, it is necessary to provide the best education for them and meet their educational needs if they are to be ensured access to the educational technology required within various instructional curricula. Finally, although Sanford (1984) did not specifically refer to independence as a reason for utilizing computers in the classroom, it may be subsumed under the category of "enhanced normalization." As such, it merits special attention when discussing the special education needs of blind and visually handicapped students and this important result of the educational use of sensory aid technology will be underscored.

An attempt will be made to document many of the educational changes that involve technology and to describe efforts to meet the special educational needs of blind and visually handicapped students. Observations made by some of the innovators regarding successes and drawbacks will be cited.

The microcomputer in evolving educational practices. The past two decades have seen major public reports concerning negative aspects of public education--declining reading, math, and science scores; increased school vandalism; and campus violence. Government reports and public concern have resulted in many changes including greater attention to science and technology. Many states are now mandating computer literacy as an academic requirement for high school graduation. Elementary schools are beginning this training as early as the primary years. Some colleges are requiring--even providing--college freshmen ownership of personal computers (Kessler, 1984). With the proliferation of computers in public school settings, a large, new industry of educational software is growing to meet and to create a demand for commercially available, educational program packages.

Scadden (1984a) documented three additional results of the public outcries caused by declining discipline and achievement within the public school systems. First, alternative schools are springing up throughout the country, and an increasing number of parents are petitioning their states to permit them to teach their children at home. Second, commercial home study, or distance education, is on the rise. Correspondence schools that were formerly almost exclusively for the provision of remedial education now offer a wide variety of degree and certificate alternatives. Finally, the rapidly growing educational software industry includes a large number of tutorial programs that permit individuals within their homes to study many academic and hobby-related subjects. The microcomputer is playing an important role in each of these three alternatives to traditional educational programs. The computer can be used to interact with an instructor located at a remote location or to provide instantaneous feedback or reinforcement to a concept being learned.

Implications of the microcomputer in the education of visually handicapped students. The implications for blind and visually handicapped students of each of the trends in education listed above are clear. If these students are to have the same advantages and alternatives as do their sighted peers, they must have access to computer programs. Many programs have been initiated to fill this potentially serious gap in equal educational opportunity. One will be discussed here because of its interesting and important findings. Others will be cited later.

Brunken (1984) described an extensive demonstration program conducted at the Nebraska School for the Blind in the use of microcomputers by blind and visually handicapped students. This study showed that the students could learn to operate microcomputers and access technology for some school-related work. Student success in the microcomputer program was affected by several factors: prior knowledge of the keyboard, development of listening skills, ability to follow directions, level of cognitive development, and general level of literacy. The Nebraska researchers found that a background in reading either braille or print increased understanding of the format of written material including paragraphing, spelling, and punctuation. Finally, this study resulted in a 10% increase in school grades by students who used microcomputers as a word processor for the preparation and editing of school materials.

The Nebraska studies should be replicated elsewhere to determine whether these findings can be generalized to other populations of blind and visually handicapped students. Nevertheless, those reports and others from model programs present research and evaluation findings that should have broad implications for the specialized training provided blind and visually handicapped students. It seems clear that: 1) Keyboard skills, or basic typing, must be taught; 2) The ability to listen and to follow directions must be taught; 3) Print or braille reading should be emphasized whenever possible; 4) Word processing should be the first skill taught with microcomputers, followed by database access skill to enable students to avail themselves of remote literature research capabilities; and 5) Specialized computer-aided instructional materials should be developed with speech output software to be used with blind and visually handicapped students.

The issue of placing emphasis upon braille reading by totally blind students, whenever possible, has been a controversial topic in recent years. Mack (1984) forcefully advocated more emphasis upon the teaching of listening skills even if it reduced the amount of training given in braille reading. Her conclusions were based upon the findings that blind adults do not use braille as much as they do audio for obtaining information and entertainment. The results from the Nebraska School for the Blind, however, would suggest that the use of braille during the educational process may contribute an important dimension to mastery of basic skills of literacy which will subsequently transfer to the broader activity of interacting with a computer. This conclusion supports the position taken by Foulke (1981), who promoted the use of braille for the teaching of mathematics and science. Further, Michaelis and Wiggins, quoted by Goodrich (1984), stated that braille and speech together provide the most effective means of reading some computer output displays, such as accounting spreadsheets.

Reading technology. The preceding discussion of the relative merits of braille and speech reading media used by blind persons leads directly to consideration of the current state-of-the-art of reading technology and expectations for the near future.

Audio cassette recordings will apparently remain the primary medium for the presentation of reading instruction material for many blind and visually handicapped students for the foreseeable future. The technology underlying the recording and playback of this material is not changing dramatically, although it is improving and the costs are declining. Speech compressors are not widely available but can be expected to continue to be of interest to many aural readers (Scadden, 1982-1983). More dramatic enhancements are being realized in the production of alternative forms of producing and presenting braille material and digitized information that can be assimilated through the sensory modality of choice.

The introduction in the late 1970's of electronic, or paperless braille, equipment provided a viable option for the storage and retrieval of braille material as well as providing a braille display for computers. These devices can store up to several hundred braille pages on a single cassette or diskette. Techniques for producing books or periodicals in this medium have been developed and are leading to increased use of electronic braille as an alternative to paper braille (Raeder, 1984).

Electronic braille, until recently, relied upon the recording of specialized codes of auditory tones on a cassette. This technique led to a wide variety of auditory coding approaches. Paperless braille tapes made for one machine have been incompatible for reading on machines made by other manufacturers. The increasing use of digitized information should lead to the capability of personal selection of the device and medium by which information is read (Deken, 1981). High density storage of digitized, electronic information can be produced by laser technology on compact discs and other emerging media. The user then can choose to have this information displayed on a print screen, speech output system, paper braille, or electronic braille display. The future of reading material is changing for all of our society, and the change should provide more educational equality between blind and visually handicapped students and those without handicaps.

Accessing printed material. Although it is essential to plan for the future, it is important to understand and to utilize the capabilities present today. Raeder (1984) described a variety of techniques that can currently be used to produce reading materials for blind and visually impaired readers. The basis for modern alternatives rests again on the fact that literary information is commonly produced and stored electronically. This information, typically prepared for transmission to an ink-printer for use by sighted readers, can be used to create reading material for blind or visually impaired readers by utilizing a different output or storage system rather than the standard printer. Again, the information could be sent to an electronic braille device or alternatively to an affordable braille embosser. It could be sent to a printer that generates large print; or finally, it could be stored on microcomputer diskettes to be used by the visually handicapped student with whatever display device is preferred.

Alternative media for storing this electronic information also exist. For example, material can be obtained from publishers on compositor or computer tapes through special permission arrangements. Although many of the printer control commands existing on these tapes must be removed prior to use with other storage or display equipment, this process provides the educational institution with a viable option for producing reading materials for special education students. A second alternative relates to the proliferation of commercial data banks that house a multitude of literary material such as journals, encyclopedias, and current events furnished by the large wire services. These can be accessed with microcomputers for storage and personal use. Third, material can be entered manually by a typist into a computer, stored, translated into Grade Two by the computer if necessary, and then transmitted to the desired sensory aid system for use by the student.

Another data entry technique that has only recently begun to be accepted as a viable and useful approach is that provided by the use of automatic scanning and optical character recognition (OCR) systems (Raeder, 1984). Print material can be placed on one of the commercially available OCR systems to be "read" by the computer. The material is digitized and either stored on a disk or sent to some other display device. The well-known Kurzweil Reading Machine that presents the output of the OCR system as synthetic speech is one form of such an instrument. This approach has wide application in the field of special education in that printed material can be produced for use in a variety of display modes. The Kurzweil Data Entry System, the DEST system, and the TOTEC are three well-known OCR devices on the commercial market, and each system continues to improve in performance and flexibility.

The publicly accessible data banks described earlier provide a valuable resource for blind and visually handicapped students for independent literature research. Scadden (in press) described the use of NEXIS, one large data service, by chemistry students for the independent access to professional journals concerned with chemistry, a subject for which it is difficult to obtain qualified readers. With microcomputers, these students have been able to obtain and read a wide range of relevant scientific material independently. Similar examples from other disciplines were cited by the author in the same paper. Blind and visually handicapped students in special education programs should be taught the techniques of accessing relevant data banks for the purpose of obtaining reading material of interest. Such independent skills will be of value within the educational setting and in activities of daily living. Thus, word processing and data bank access are two important reasons why blind and visually handicapped students should be taught the use of microcomputers (Scadden, 1983a; 1983b).

Scientific laboratory sensory aids. In a later section of this paper concerned with vocational education, the importance of the growing number of career opportunities in the sciences will be discussed with emphasis upon the need for enhanced scientific educational possibilities for blind and visually handicapped students. Morrison and Lunney (1984) extensively documented the history of increased laboratory opportunities for blind and visually handicapped students. They stressed the need for improved technology for all laboratory sciences, giving special attention to their discipline of chemistry. In this review, the authors described instrumentation that will provide blind and visually impaired science students independence and flexibility within a science curriculum. In the past, such students have fared adequately within classroom activities, but they have not had the independence within the laboratory environment necessary to provide them with the experiences required for the mastery of competitive scientific skills.

Now that the majority of scientific laboratory observations and measurements are being made with the aid of complex instruments, the independence and competitiveness of blind and visually handicapped students can be developed if the appropriate output displays can be provided for the measurement instruments. Morrison and Lunney (1984, p. 418) summarized this advocacy position: "Indeed, if a visually handicapped student plans to do laboratory work as a scientist, technician, or engineer, he or she will have to operate apparatus independently, so why should the student not start early with the right tools?"

Morrison and Lunney (1984) described the development of scientific measurement equipment for visually impaired science students that has been named the ULTRA (the Universal Laboratory Training and Research Aid). The ULTRA has been designed to provide the blind or visually handicapped student with a self-contained microcomputer that can be used for computational and word processing activities as well as to provide them input from a wide variety of laboratory measurement devices commonly used in chemistry, physics, geology, and other sciences. The output for this system could be synthetic speech, braille, large-print, or a series of tonal patterns depending upon the availability of display technology and upon the specific application. Further research and evaluation of this system is needed, but the ULTRA appears to provide an enriched future for blind and visually impaired individuals desiring to enter scientific disciplines. The ULTRA has also been designed in a modular fashion so that it can be updated expeditiously and relatively inexpensively.

CAREER EDUCATION AND VOCATIONAL TRAINING

Special education professionals concerned with providing guidance and/or training to blind and visually handicapped students for future employment activities must be cognizant of the trends in the national labor market. Technology--especially the microcomputer and its peripheral sensory aids--will be important in achieving competitive job readiness skills for individuals with visual impairment. A number of reviews of the current use of technology by blind and visually impaired workers have described the trends observed today and forecasted for the remainder of this century (Goodrich, 1984; Scadden, 1982-1983; Scadden, 1983b; & Scadden, 1984a). The following paragraphs will highlight the major observations of these reviews that are relevant for career education and vocational training professionals in the special education of blind and visually handicapped students.

The information economy. Most economists and futurists state that our society is changing from one based upon industrial manufacturing to one based upon the creation and distribution of information. Naisbitt (1982) presented a series of statistics documenting the change in the nation's labor force. In 1950, only 17% of the labor force worked primarily with written information, that is, materials such as correspondence, reports, invoices, receipts, forms, diagrams, and specifications. In today's labor force, over 60% of the workers are so employed. Simultaneously, fewer individuals are engaged in the direct manufacturing of goods. Perhaps the most important aspect of these changes in career activities, as they relate to the blind and visually impaired worker, is the ever-increasing use of electronics in the creation, processing, and distribution of this information. The importance of the computer in these activities is accelerating.

Predictions differ widely regarding the magnitude and timing of the computer's impact upon the labor force, but most futurists agree that over 60% of the work stations in the United States by the year 1990 will be electronically based. In other words, there will be a computer or microprocessor involved in the processing and display of information of some kind with which the worker must interact. It is clear that people who cannot successfully interact with these displays will be at a severe disadvantage in the labor market. Scadden (1984a) stated that these data must impact the special education and rehabilitation professions:

> Thus, it is essential that all necessary provisions and training be made available to blind and visually impaired individuals. It requires that appropriate, high quality speech and tactile computer displays and support software be developed and distributed and that blind and visually impaired individuals have access to educational and training programs that will prepare them for the employment world of tomorrow. (p. 395)

Scientific careers. Toffler (1980) identified four clusters of industry that will experience rapid growth in the coming decades, which along with the existing three largest industries (steel, automobiles, and chemicals), will dominate the industrial economy in the future. These four industrial clusters are the following: electronics and computers, space, oceanographics, and the biological sciences. Each of these clusters, together with chemicals, emphasizes the sciences. Even the remaining two large industries, steel and automobiles, employ a large number of engineers and scientists. The remainder of the overall economy will be dominated by government and service industries that again are composed mainly of workers engaged in the manipulation of information.

The "knowledge worker". The term "knowledge worker" has been coined to refer to the large number of individuals who work with ideas, concepts, and information. The review of the industries and businesses that will serve as the backbone of the future's economy results in the unequivocal realization that career education and vocational training must emphasize the significance of preparing for employment as a "knowledge" worker whenever possible and appropriate.

Blind and visually impaired individuals have the opportunity to compete fully in the primary activities of the "knowledge" worker in the creation, transmission, and monitoring of symbolic information given the appropriate information display and adequate educational training.

Decentralization of employment. With the wide dissemination of computer and telecommunication technology, millions of jobs could be performed from home or other remote locations because the nature of the work involves the creation and distribution of symbolic information. This fact is leading to a decentralization of the national labor force, according to economists and other social scientists (Deken, 1981; Toffler, 1980). A microcomputer and a telephone link will be sufficient to tie many workers and small business establishments to more centralized facilities.

Two kinds of workers are emerging in the decentralized work force: the telecommuter and the "electronic cottage industry" worker. The telecommuter is the employee of a firm who conducts assigned tasks from a remote site and interacts with the central facility by way of a computer and telecommunication equipment. The "electronic cottage industry" worker is the individual who is self-employed or who works for a small business engaged in the creation, processing, and/or transmission of electronic information. Such small businesses sell their services to other individuals, larger firms, or organizations. Small electronic firms are springing up across the country selling such services as the design of new products and software, the handling of paperwork and files for larger institutions, scheduling for local transportation services, data processing and accounting services, word processing and payrolling, and marketing. Some small entrepreneurs are providing management services for other small businesses.

The decentralization of employment must be considered in determining viable career options for blind and visually impaired individuals. It cannot be permitted to become a stereotyped solution to vocational rehabilitation needs of this population. Home-based employment can create isolation from the rest of society; thus this employment option must be retained only for those without other feasible opportunities and for those who choose it. Nevertheless, with appropriate training and technology, telecommuting and small electronic entrepreneurial activities serve as innovative alternatives.

Employment opportunities for multihandicapped visually impaired individuals. Even the "non-knowledge" worker of the future will often require access to computerized information. Manufacturing is already becoming computerized with the advent and increased use of processes known as "computer assisted design" and "computer assisted manufacturing," CAD-CAM. In these processes, for a long time in the future, there will still be human workers employed to monitor computer activity. The computer information will be displayed visually, auditorially, or even tactually. Toffler (1980) proposed that many of these repetitive, monitoring tasks could be performed by individuals with lower intellectual capabilities because the information could be presented through voice synthesis with detailed instructions of step-by-step actions to be undertaken. Scadden (1984a) carried this principle a step further to suggest that many of these tasks were within the capabilities of numerous multihandicapped blind and other disabled individuals, given the appropriate displays, training, and response systems. Considering the large number of multihandicapped blind and severely visually handicapped students present today within the special education programs in the country, these options must be systematically investigated. In many situations, the multihandicapped blind worker will require alternative input techniques because neither the standard keyboard nor the visually mediated keyboard emulators commonly used with sighted orthopedically handicapped computer users are appropriate. Speech recognition systems or aurally mediated keyboard emulators must be developed and tested for these individuals.

Synopsis of career education needs. In conclusion, it is clear that career education and vocational training must take into consideration societal and economic changes. A report of the U.S. Office of Technology Assessment (1982) stated that,

> modern society is undergoing profound technological and social changes brought about by what has been the information revolution ....A key element of all of these educational needs is that they will constantly change. In a rapidly advancing technological society, it is unlikely that the skills and information base needed for initial employment will be those needed for the same job a few years later. Lifelong retraining is expected to become the norm for many people. (pp. 1-2)

SPECIAL EDUCATION PROFESSIONAL PERSONNEL PREPARATION

Since the completion of the Bureau of Education for the Handicapped's national Optacon Dissemination Program, and its concurrent special educator Optacon training program conducted by the University of Pittsburgh, there has not been a strong or systematic national effort relating to the preparation of special education personnel in the field of technology for blind or visually handicapped students. Of course, many pockets of inservice teacher training related to technology exist within individual teacher preparation programs, such as at Peabody College, Vanderbilt University; Teachers College, Columbia University; Northern Colorado University; San Francisco State University; and California State University, Los Angeles. These latter programs deserve credit for their attempts and their successes, but to date, they have not had the resources to provide either the breadth or depth of training necessary to impact the needs of the vast majority of the nation's blind and visually impaired elementary and secondary level students.

The Optacon Dissemination Program was unique in that the personnel training provided was related directly to the provision of an Optacon to a specific school district. In this case, the specific technology "drove" the personnel preparation activity. There is no reason to anticipate that similar sensory aid dissemination programs will emerge in the foreseeable future. Thus, the successes of the University of Pittsburgh in training over 1,000 special educators in the use of educational technology (Heubner, 1980) may not be generalizable to future situations. The majority of the activities prevailing within the university-based special education personnel preparation programs that relate to technology for the blind and visually handicapped student are conducted as inservice, summer programs. The one exception has been the Peabody graduate program that accepts applications from special educators interested in pursuing advanced degree studies related to the application of sensory aid technology to the needs of blind and visually handicapped students. Although only a few individuals have received this advanced training, the program has succeeded in increasing the body of knowledge in this field through the conduct of research and demonstration programs. (For example, the entire special issue of Education of the Visually Handicapped that was devoted to microcomputer technology was based upon activities of individuals connected with the Peabody program.)

STATE OF PRACTICE

Gaps between the emergence of new technology for the blind and visually handicapped student and its utilization must be anticipated on economic grounds if on no other. Sensory aid devices are commonly expensive, a problem that is virtually impossible for the manufacturers and distributors to remedy based upon the low prevalance population being served. Economy of scale production permitted by increased quantities can never be realized as the means to reduce the unit cost of these aids. Thus, school districts, institutions, organizations, agencies, and individuals alike, must budget in advance to acquire the funds necessary to procure needed instrumentation.

An additional problem confronting some users of sensory aids has been produced by the fact that technology in general in our society is changing so rapidly that sensory aids designed to provide suitable output for some device, such as a computer, may not be appropriate for the next generation of the device. This problem has not as yet been acute within special education because educational facilities are not able to upgrade rapidly to advanced technological systems. However, it has been a problem in many institutions and agencies engaged in vocational training. An example of this gap caused by timing may be in order. In 1980, IBM released the Audio Typing Unit, a system designed to provide blind word processor operators full vocabulary screen review capability when using the IBM MagCard word processor product line. Unfortunately, this speech system had been under development for several years, and by the time it was ready for the marketplace, the word processors for which it was intended were not commonly being used. A number of vocational training facilities adequately trained students on this system only to find that competitive jobs were not available. Fortunately for many students, word-processing skills can readily be transferred from one machine to another. For those who could find adequate output displays for newer machines, the training was valuable. For many others, it failed to lead to productive employment.

Data on the number of microcomputers in school districts in the nation cannot be fairly compared to data on the percentage of visually handicapped students receiving microcomputer training. Anecdotal data, however, from many special educators and sensory aid distributors, suggest that a gap bewteen knowledge and practice probably exists. It is clear that blind and visually handicapped students can profit as much, and probably more, from the use of microcomputers in schools than their fully sighted peers. Many blind and visually handicapped students are not able to participate in "computer literacy" courses in mainstream programs because appropriate sensory aid display technology is not available. Despite this discrepancy between research results and educational practice, there are numerous exemplary programs that illustrate that modern technology is being used and research findings are being implemented in many locations. Some examples will be briefly described.

The Peabody College program. The Peabody College microcomputer program, entitled "Research on Multimedia Access to Microcomputers for Visually Impaired Youth" (Ashcroft, 1984), supported by the U.S. Department of Education, has investigated techniques for providing access to microcomputers for this population of students. Several residential and public school programs have participated in this research and demonstration effort. Results have demonstrated that blind and visually handicapped students can learn to operate microcomputers and sensory aid access technology, and perform school assignments more independently and with higher grades (Brunken, 1984).

The Peabody program had several objectives, including the following: To study microcomputer systems that would be made accessible to visually handicapped students through touch, voice, and large-print; to develop and evaluate instructional programs for teaching visually handicapped students to use these multimedia microcomputer systems through access technology; and to develop and evaluate instructional material for inservice and preservice training of educational personnel. Documentation of the program successes and use of curricular materials including software packages are available from the institution. These materials should be of value to professional personnel training programs initiating their own curriculum relating to the use of technology for the education of blind and visually handicapped students.

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The Nebraska School program. One of the institutions participating in the Peabody project was the Nebraska School for the Visually Handicapped. Brunken (1984) described the Nebraska program and its findings. This demonstration project developed eight levels of microcomputer utilization for the participating visually handicapped students. The program activities were the following: 1) Tutorial activities related to repetitive tasks encountered in such courses as spelling, typing, math, science, social studies, and language arts; 2) computer literacy; 3) prevocational training related to skills required in careers that utilize computer technology; 4) personal applications of microcomputer and sensory aid technology; 5) computer programming; 6) career planning through the exploration of different careers described in specially developed computerized materials; 7) word processing; and 8) the administration of files.

The Sensory Aids Foundation program. The Sensory Aids Foundation (SAF) studied the effectiveness of using Apple computers with blind and visually handicapped elementary students in the San Francisco Bay Area. This study (Sensory Aids Foundation, 1984) found that Apple microcomputers could be operated successfully using speech synthesizers. However, many commercially available educational software packages were inaccessible to blind students using speech output because the programs were protected from transmission to peripheral devices. Similar limitations have been noted by Brunken (1984) and Young (1984). Brunken (1984) stated that visually handicapped students, using large-print displays, had greater access to these programs because they could frequently use the video screen rather than an audio display. Special software is available from SAF.

Software evaluation. Ashcroft (1984) emphasized that any practitioner interested in utilizing commercial software must carefully evaluate the programs first. The criteria proposed for use in this evaluation process include: determining its effectiveness, ensuring that it can be used with the desired access technology, avoiding programs in which time of response is significant, and identifying software in which pictorial or graphic information is minimal.

Summer training programs. A number of summer programs have been held to provide microcomputer experience to blind and visually handicapped students. One summer camp devoted to this activity has been described by Farrera and Murray (1984). This program, conducted in Houston, was for teenagers who differed widely in background and intellectual capability. The "computer camp" concept appears to warrant replication in other locations.

An additional approach to providing an introduction to microcomputers for blind and visually handicapped students is that offered through a home study, correspondence course from The Hadley School for the Blind (Scadden, 1983a). Blind and visually handicapped students enroll in a four-part course on microcomputer and sensory aid access technology. Some augmentation is offered through hands-on experience provided by collaborating rehabilitation and educational facilities.

The summer training program concept has also been used successfully for inservice training of special educators in the application of microcomputer and sensory aid access technology. Professional personnel training programs such as those offered at Teachers College of Columbia University, the University of Northern Colorado, San Francisco State University, and California State University at Los Angeles are four examples of such programs.

An additional summer program, conducted for teachers by a private rehabilitation agency, merits special attention. The Carroll Center for the Blind has conducted summer programs for teachers of blind and visually handicapped students in the use of microcomputers and sensory aid technology. Instructional materials were developed under a grant from the Rehabilitation Services Administration and have been made available to interested individuals. These Carroll Center programs have received positive evaluations from participants.

Availability of sensory aids in institutions of higher learning. On the college and university level, blind and visually handicapped students have begun to receive the technology necessary for increased independence and competitive productivity. Kessler (1984) described needs of the visually impaired college student and the attempts of one institution, the University of North Carolina, to meet these needs. Morrison and Lunney (1984) described the research at East Carolina University that should increase the ability of blind and visually handicapped students at all levels to compete successfully in scientific disciplines. Finally, an example of a statewide effort to make computer technology accessible to blind and visually handicapped students is provided by the current activities of the Commonwealth of Virginia. With a grant from the U.S. Department of Education, the Virginia Department for the Visually Handicapped is investigating the computer needs of blind and visually handicapped students on each of the state's college and university campuses. Appropriate hardware and software are purchased and installed on selected campuses as demonstration projects. To date, the Department has determined that computer usage is required in virtually all curricula in the mid-1980's--business, education, law, the humanities, and science and engineering.

The Xerox Corporation awarded 100 colleges and universities Kurzweil Reading Machines for use by blind and visually handicapped students. Although many of these machines have not received adequate usage, an increasing number of institutions are finding innovative ways of utilizing the optical character recognition capability of these systems for the production of reading materials in paper braille, on electronic braille cassettes, or on microcomputer disks. Information regarding these applications should be disseminated more widely so that other students can benefit from similar capabilities of machines that are currently idle.

Literacy training. Another area in which there appear to be discrepancies between knowledge and practice relates to the universal instruction of basic literacy skills to blind and visually handicapped students. The Brunken (1984) observations that students with language skills show better progress in microcomputer training than did those without such skills are supplemented by many anecdotal reports from computer training programs. Alarm is being expressed over the number of blind and visually impaired high school graduates who are not proficient in literacy or writing skills.

In June 1984, in a paper presented at a National Conference on Literacy and Disabled People, Scadden (1984b) said that this problem has arisen both from inadequate instruction and from a lack of rigorous demand for independent demonstration of individual competencies. Further, he stated that,

> Partial blame can also be placed at the doorstep of technology which has led many educational systems to encourage blind students to learn reading and writing skills solely through auditory techniques. Many blind students never master braille reading and writing skills. Critics of braille correctly state that recordings are less expensive than braille, readily obtained, and easily stored....However,...the mechanics of spelling and grammar are mastered more rapidly by blind people by reading tactually and through practice in the creation of written passages. in a culture and an economy which emphasize written communication, to be fully competitive in information related careers, disabled and nondisabled people alike will have to be proficient in language arts. (p. 13)

At this national literacy conference, U.S. Secretary of Education T. H. Bell stated that one objective of the national education program should be to help students learn to help themselves. Assistant Secretary Madeleine Will embellished this theme in direct reference to disabled students by saying that, "We must work to decrease their dependency." She continued by saying, "We should encourage all students to perform at the boundaries of their personal limitations." Educational practices may not be fully in line with these objectives considering the performance of many visually impaired high school graduates. Efforts must be made to increase the independence and the productivity of these students. The use of appropriate technology in many educational activities can contribute significantly to this goal.

In conclusion, it must be emphasized that the objective of improving the educational opportunities of blind and visually impaired students through the application of technology can be achieved only by ensuring that educational professionals are adequately trained in the use of these products.

Dissemination of relevant information concerning research and demonstration activities must be enhanced. The normal means of using publications and public presentations at professional conferences must be continued, but the number of inservice training programs must be increased. Funds for providing educator stipends are needed to promote participation in these training programs. The use of telecommunication networks such as SpecialNet and of teleconferencing techniques must also be promoted, for dissemination of information both by the innovators and by the special educators desiring new ideas, concepts, and practices. With such efforts, special educators can help guarantee that blind and visually impaired students will benefit from the new possibilities promised by modern technology.

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THE USE OF TECHNOLOGY IN EDUCATIONAL PROGRAMS FOR STUDENTS WITH MULTIPLE HANDICAPS

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Despite the legal assurance of an appropriate education for all students with handicaps, the provision of services for low incidence populations, in this case, those students with severe, multiple handicaps, continues to generate controversy. In courtrooms and in professional writings, the question of "educability" has been debated (Baumeister, 1981; Burton & Hirshoren, 1979; Lehr & Brown, 1984; Noonan, Brown, Mulligan, & Rettig, 1982; Sontag, Certo, & Button, 1979). On one side, there is the argument that some individuals are incapable of learning a significant number of meaningful skills (Kauffman & Krouse, 1981). "Heroic" efforts to train unresponsive individuals are considered harrassment by those who feel these expectations are inappropriate (Bailey, 1981).

In contrast, the belief that all children with handicaps can profit from education is based on a different set of assumptions. One is that "educability" is now a legal concept (Martin, 1981). The fact that the term may have originated with, and retains an academically oriented meaning among educators, is no longer of consequence. Philosophically, current policies regarding the education of students with handicaps are attributed to a set of generally accepted social and political values. According to Turnbull and Turnbull (1978), a belief in the essential sameness of all persons, that government benefits should not be contingent upon unalterable characteristics of a person, and the belief that education makes a difference, are assumptions that have influenced public policy on behalf of students with handicaps.

From a pragmatic perspective, recognition of the limitations of present instructional technology, as well as the inadequacy of previous and current services, prohibits definitive conclusions regarding educability or its limitations (Orelove, 1982). In a discussion of his testimony in the Wyatt V. Hardin right-to-treatment case (Petitioner's Motion for Modification, 1978), Baer (1981) concludes "I have failed to teach quite some number of profoundly retarded children, yet in the face of such failure I have succeeded often enough in teaching them by trying something different (not always--just often enough) that I will affirm, not as a statement of fact but as a statement of policy, that I will proceed as if all children are capable of learning under instruction (p. 93)."

Low incidence populations constantly challenge the educator's abilities, practices, and creativity in the search for that "something different" that will be successful in instructional programs for these students. Advances in the field of microtechnology have led to the development of new tools that hold great promise in providing instruction and increasing a student's independence. Technology can also assist the teacher in performing time-consuming program support activities. After establishing important characteristics of instructional programs for students with multiple handicaps, the role of technology in providing these services will be examined. Direct applications with students, as well as program support and management activities, will be considered.

PROGRAM GOALS FOR LOW INCIDENCE POPULATIONS

Since the mid-1970's, services for students with severe handicaps have undergone a major transformation. Programs which emphasized care in segregated settings have been challenged to adopt and operationalize the "criterion of ultimate functioning," the belief that the demands of a full range of normalized school, work, and community settings should guide the selection of training goals and activities for students with severe handicaps (Brown, Nietupski, & Hamre-Nietupski, 1976). A developing instructional technology is being used to provide training that utilizes "real" materials and naturally occurring cues and consequences in the context of functional activities in integrated settings.

This orientation may not seem readily relevant to the work of the teacher of a high school student whose assessments indicate that he or she is functioning at the 6- to 12-month level. However, a second premise underlying curricular decisions for students with severe handicaps, the principle of partial participation (Baumgart et al., 1982), relates to this concern. Recognizing that not all students with severe handicaps will be able to acquire skills that enable them to function independently in a range of school and nonschool settings, the principle of partial participation states that involvement to the greatest degree possible is preferable to exclusion from these activities. Through direct and systematic instruction, students should be taught those skills that will allow them to function, at least in part, in a variety of normalized settings.

TECHNOLOGY AND PARTIAL PARTICIPATION

In practice, planning for partial participation usually requires the use of some type of adaptation, that is, an adjustment or modification that allows or increases the degree to which a person can participate in an activity. As described by Baumgart et al. (1982),

> An individualized adaptation is one that is personalized and enables a particular student to participate at least partially in a particular chronological age appropriate and functional activity. This is done by enhancing the performance of existing skills, compensating for missing skills that will not likely be acquired, and allowing for the acquisition and utilization of alternative skills. (p. 20)

Adaptations vary considerably in the means and degree to which they enable an individual to participate in an activity. Some adaptations can be described as contextual, in that they involve minor changes in the environment. Providing personal assistance is probably the most frequently used adaptation

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of this type, for example, pulling the lever on a vending machine to get the item to which a student has just pointed. A rule change, for example, allowing a student to begin changing classes slightly before the bell rings so that he will get to the next activity on time, is another type of contextual modification.

The introduction of specialized materials and devices represents a "technological" approach to partial participation. Special educators have long recognized the value of these innovations in maximizing students' development or in overcoming barriers to their participation (Joiner, Sedlak, Silverstein, & Vensel, 1980). While sophisticated devices such as the Optacon, talking calculator, or paperless braille machine may come to mind, there are many "low tech" strategies that are widely used with students who have multiple handicaps.

A program developed for an adolescent with severe handicaps, described by Browder and Martin (1986), exemplifies the use of the principle of partial participation and its accompanying individualized adaptations within the framework of a functional "life skills" curriculum. They present Tommy as a 12-year-old who lives in a residential facility for individuals classified as severely and profoundly mentally retarded. His strengths and weaknesses are described as follows:

> He has spastic quadriplegia, seizures, scoliosis, and severe asthma, and does not respond to visual stimuli. Tommy is able to voluntarily move one arm, nod his head, smile, laugh, and cluck his tongue. Before his new curriculum was implemented, he had no recognizable expressive communication. On the Bayley Scales of Infant Development and the Vineland Social Maturity Scale, Tommy has scored below the 2-month level. Tommy's individualized education program (IEP) has included skills from the 2- and 3-month developmental level for his entire school career. In the past, his lack of progress has been attributed to the severity of his handicaps. (p. 261)

In preparing a comprehensive program for a student of Tommy's age, developmental scales are quickly abandoned as a basis for selecting program goals. Instead, an ecological inventory (Brown, Branston, Hamre-Nietupski, Pumpian, Certo, & Gruenewald, 1979) was conducted by the teacher in conjunction with Tommy's grandmother. The purpose of this inventory was to identify current and future residential, recreational, and work settings. A comparison of the skills required to participate in these settings with Tommy's current abilities led to the identification and prioritization of his educational needs. Briefly, the following settings, skills, and activities were selected.

1. Current Environments--Presently, Tommy spends all his time in his medical residence and his grandmother's home.

2. Future Environments--Tommy's grandmother wants him to accompany her to community settings, such as a shopping mall and restaurant. His teacher identified environments that would provide Tommy with

recreational, vocational, and community experiences. These included the local YMCA, community-based health facilities, a van for transportation, the senior citizen center in which his grandmother lived, and a group home.

3. Current Abilities--Skill deficits which had led to Tommy's exclusion from most activities included the lack of a communication system, poor head control, lack of physical stamina, and severe asthma. These deficits also resulted in total dependence upon others to perform life skills.

4. Skill Assessment--The teacher undertook several assessments to identify a starting point for instruction. Assessments were conducted to identify a reliable response which might form the basis for a communication system and a movement which could activate a switch to provide recreation and vocational opportunities. Tommy's physical stamina was assessed by determining his tolerance for wheelchair travel. His tolerance for water was evaluated by placing him in a wading pool. Finally, the teacher assessed his ability to participate in his daily routine.

5. Assessment Results--The teacher found that in response to recorded tapes of Tommy's grandmother, his most consistent voluntary response was a clucking of the tongue. Observing Tommy's efforts to activate his tape recorder, his range of motion was assessed. He could not use his hands; however, he was able to move one arm vertically and horizontally, approximating the response needed to activate a flipper switch. In a wheelchair, Tommy did not hold his head up independently. If pushing the chair was made contingent upon holding his head erect, Tommy did demonstrate the ability for short periods of time. Tommy startled and tensed when placed in the water of a wading pool. Finally, he was observed to smile during dressing in response to comments about his clothes, could hold his head up when the teacher put his t-shirt on, and lowered his arms after they were put in the sleeves.

6. Training Goals--The following skills were identified as priority training goals for Tommy:

   - a yes/no communication system
   - partial participation in self-care routines
   - use of a flipper switch
   - tolerance for wheelchair travel

7. Training Activities--In keeping with the concept of the criterion of ultimate functioning, these skills were taught in the context of real life activities. His curriculum plan, as delineated by Browder and Martin (1986), is summarized in Table 1.

Table 1

Tommy's Curriculum

DOMAIN: Domestic

ENVIRONMENTS: Current: Medical residence
Grandmother's home
Future: Group home

Subenvironments	Priority Activities	Priority Skills for IEP
Bedroom	Participating in dressing	1. Communicate choice 2. Move arms to help put shirt on
	Ringing buzzer for help	1. Activate switch 2. Respond to yes/no questions
Bathroom	Participating in bathing	1. Move arms on command 2. Maintain head control 3. Participate in face washing
	Participating in personal hygiene	1. Communicate need to be changed
Dining Room	Eating	1. Communicate choice 2. Indicate when full 3. Drink from a straw
	Socializing	1. Eat in presence of people and noise 2. Communicate greetings 3. Wait turn to be fed without crying
Living Room (see Recreation)		

Table 1 (continued)

DOMAIN: Community

ENVIRONMENTS: Current: Travel
Senior citizens center
Future: Shopping mall
Restaurant
Community physician's office

Subenvironments	Priority Activities	Priority Skills for IEP
Car or Van	Traveling without one-to-one assistance	1. Maintain head control 2. Tolerate chair 3. Maintain body alignment
Senior citizens lounge	Socializing	1. Give gifts 2. Use yes/no communication with strangers 3. Play cassette tapes for others
Stores	Buying clothes	1. Communicate choice 2. Maintain head control 3. Tolerate chair
Physician's office	Cooperating with examination	1. Use yes/no with doctor 2. Tolerate examination
Dining area of restaurant	Eating	1. Drink with straw 2. Eat in strange setting 3. Communicate choices
Living room (see Recreation)		

Table 1 (continued)

DOMAIN: Recreation

ENVIRONMENTS: Current: Medical residence
Grandmother's home
Future: YM/YWCA
Events at theater or college

Subenvironments	Priority Activities	Priority Skills for IEP
Living Room	Listening to tapes	1. Select tape 2. Activate switch to turn tape player on/off 3. Ring buzzer for help to change tape
Library/living room	Listening to stories read from books	1. Select book 2. Respond to yes/no questions about book
Outdoors	Swinging in wheelchair swing	1. Indicate desire to swing and to stop 2. Maintain head control on swing
	Taking walks in wheelchair	1. Maintain head control 2. Tolerate chair for longer periods of time 3. Respond to yes/no questions about outdoors
Pool	Swimming	1. Indicate desire to get in/out of pool 2. Tolerate water 3. Move arms independently
Theater/bleachers	Observing events	1. Maintain head control 2. Indicate needs (e.g., thirst, hunger, personal hygiene) 3. Respond to yes/no questions about the event

Table 1 (continued)

DOMAIN: VOCATION

ENVIRONMENTS: Current: Medical Residence
Future: Senior citizens center other residences as audiovisual assistant

Subenvironment	Priority Activities	Priority Skills for IEP
Lounge/living room	Running audiovisual equipment that has been set up	1. Activate switch for on/off 2. Ring buzzer when equipment malfunctions or movie or tape is completed

MICROCOMPUTER APPLICATIONS

Would a microcomputer make any difference in a program for Tommy or students like him? Based on current software and peripheral availability, instructional and management functions which could be performed with the assistance of a microcomputer will be described.

Instructional Applications

Response-contingent learning. Studies of early learning have revealed that infants are highly competent, making a connection between an operant response and its related environmental stimuli as early as 2 months of age (Hulsebus, 1973). Watson (1966) first suggested that "contingency awareness" was the basis for a generalized cognitive awareness of the relationship between behaviors and their consequences. Research has demonstrated the importance of contingent feedback in the context of both physical and social interactions (Brinker & Lewis, 1982a) and its subsequent impact on the motivational, cognitive, attentional, and affective behavior of infants (Hanson & Hanline, 1985).

Students with significant handicaps are at great risk in regard to the development of contingency awareness. The presence of sensory and motor impairments restricts opportunities to experience a variety of physical contingencies. Social contingencies may also be disrupted between the child and his or her parents, who are unprepared to effectively interact with a handicapped child, or between children and their many caretakers in a residential facility. Without an opportunity to learn that their actions can affect and control the environment, many children with handicaps exhibit "learned helplessness," an extreme passivity and disinterest in their environment (Seligman, 1975).

Special planning and environmental modifications are necessary to enable many of these students to learn response-contingent behavior. Electromechanical and adaptive devices have been effectively used to provide contingent feedback in teaching students to increase the incidence of low frequency behaviors (Hanson & Hanline, 1985; Haskett & Hollar, 1978). However, most students will require systematic instruction to establish and maintain the responses required to activate these devices (Meehan, Mineo, & Lyon, 1985). Computers have been used for this type of instruction, both as a means of activating other devices (Brinker & Lewis, 1982b), and as a source of feedback.

The advantages of electromechanical devices have been described by Hanline and colleagues (Hanline, Hanson, Veltman, & Spaeth, 1985) as follows:

- A wide variety of activating devices are available to accommodate different physical, cognitive, and sensory impairments.
- They are motivating to children because they provide new and salient feedback.
- They may be reinforcing to students who are not responsive to social reinforcement, or those whose sensory impairments limit the reinforcers available to them.

- They deliver consistent, immediate feedback.
- The feedback and the child's response are related, providing a functional interaction with the environment.
- Minute changes in behavior can be detected.
- These activities can be used to supplement other contingency experiences provided by teachers and parents.
- Materials are durable, nonconsumable, and can be used by more than one child (pp. 20-21).

In such computer use, it is necessary to have an effective means of input for the student. A wide variety of single switch devices are commercially available (see resource list at the end of this chapter). In addition, switches can be economically constructed by instructional personnel (see Burkhart, 1980, 1982) to accommodate most students. Several software programs are available to assist in the identification of an effective switch input for a given child (Expert Systems Software, Inc., 1985; Rushakoff & Hansen, 1984). A common feature of these programs is the computer's calculation and storage of response latency, that is, the amount of time required for a student to activate a switch after a stimulus has been presented. By comparing a student's performance across different input devices and placement configurations, the combination which results in the most proficient performance can be systematically determined.

Once an effective input has been identified, several games which require single switch input are available to enable students to engage in response-contingent activities (e.g., Motor Training Games; Switch Master). Although this type of software is rather limited in scope, it is possible to adapt off-the-shelf programs with engaging graphics and animation for student use with a single switch. The Adaptive Firmware Card (Adaptive Peripherals, 1983) is a device which provides transparent access to the Apple IIe computer for individuals who are unable to use the standard keyboard. When the card is activated, a scanning array is superimposed on the bottom of the screen. By activating a single switch to stop a moving cursor, a student is able to enter a response without using the keyboard. Customizing capabilities of the Adaptive Firmware Card enables the teacher to design a scanning array for a particular piece of software, including only those numbers or letters required to use the program. Through careful selection and customization, engaging, age-appropriate activities can be developed for students with limited physical and/or cognitive abilities.

Students are also able to input responses in the computer through the use of some type of membrane or touch sensitive surface. The Unicorn Board, used in conjunction with the Adaptive Firmware Card, provides a large surface which can be defined to mean any character or set of characters which the student requires in order to use a program. A light touch on this surface is then conveyed to the computer as input. The Touch Window (Personal Touch Corporation, 1985), another alternative to keyboard input, is a device which can be mounted over the monitor, acting as a touch-sensitive screen. It can also be used horizontally as a graphics tablet or a large switch.

Choice-making. Switch activity, while important for the development of contingency awareness, is not an end in and of itself. Rather, switch activation is the first step in using technology for more advanced and meaningful activities. One of these is the ability to make choices. Until recently, curricula for education of students with severe handicaps neglected the behavior of making choices or decisions, and of expressing preferences (Guess, Benson, & Siegel-Causey, 1985). A conscious effort to provide these opportunities is critical for individuals for whom such ability is not evident and who have limited response repertoires available to them.

The choice-making activity most frequently seen in classes for students with severe handicaps is the selection of reinforcers (Raschke, 1981). The Toy Preference program accompanying an interface device called the Omni Box (Expert Systems, Inc., 1985) assists a teacher in sampling a child's reinforcement preference from among up to four different battery operated devices at one time. While this information can be used by adults to structure an instructional situation which is likely to result in optimal student performance, the activity is also valuable in and of itself as a vehicle to teach the expression of preferences.

Choice Maker (Lahm, 1985) is another program designed to enable students with limited response repertoires to control their environments. Through a series of nine carefully structured lessons, students are taken from the point where they learn that a switch will activate a battery operated toy, to the point where they can express preferences by selecting one of four switches which activate different devices.

Communication and environmental control. Technological advances have increased the range and efficiency of electronic communication devices available to students with severe handicaps. For students with multiple handicaps, however, nonelectronic systems which are simple and concrete are often the method of choice. Nevertheless, some inherent drawbacks to nonelectronic systems, as well as the changing communication needs of a student, may warrant the consideration of a more complex system in some situations.

Advantages associated with electronic systems for students with severe handicaps have been described by Hooper and Hasselbring (1985). The following are among the advantages for students with multiple handicaps.

- Electronic aids can reduce the number of movements needed and increase the rate of communication, reducing the fatigue a student experiences.

- A large number of language items can be directly accessed by the child.

- The child can access the board without assistance and the message can be "stored" on the display until someone is able to acknowledge its occurrence.

- The electronic aid may allow a broader audience to communicate with the child, especially if the aid has an auditory speech mode.

- Many electronic systems provide the child with a permanent product of his or her communication that can be used to communicate to individuals who are not in the immediate environment (pp. 40-41).

The addition of a voice synthesizer, specialized input devices, appropriate software, and a printer turns a computer into a flexible electronic communication device for students with a wide range of handicaps. Its use as a beginning communication device for non-oral students with physical handicaps is exemplified by the work of Meyers (1984). With the computer, Meyers seeks to emulate the dialogues that occur between the child and his or her caregiver during play routines. These interactions enable children to successfully communicate through gestures, vocalizations, and the manipulation of objects.

Meyers describes one effort involving a 26-month-old child who was nonvocal, blind since birth, and who had cerebral palsy. Based on information provided by the parents, an intervention based on the child's preference--having songs sung to him--was designed. An Apple computer was equipped with a membrane keyboard and voice synthesizer, programmed so that when it was touched, the word "sing" was spoken. Through a gradual shaping process, the child's motor responses became coordinated and a causal relationship between the keyboard and the vocal response was established during interactions with his mother. After the child had learned that he had to touch the keyboard in order to get his mother to sing, the same strategy was extended to other situations, for example, asking for more food when eating, asking to hold his favorite toy. In the future, the keyboard would be expanded so that he could sequence words, such as "more," "sing," and "eat."

Other available programs turn the computer into a communication device rather than a tool to promote communication (Cohn, nd, a, b; Rushakoff, 1984). While accessible through specialized inputs, these programs require significant cognitive skills on the part of the user.

Recreation and leisure. Without systematic instruction, students with severe handicaps frequently fail to develop a repertoire of skills that enable them to occupy their leisure time constructively (Wehman & Schleien, 1981). Yet, having leisure skills increases a student's opportunities for involvement with others. Leisure skill instruction has been associated with the development of collateral skills (Voeltz & Wuerch, 1981) and the reduction of maladaptive behaviors (Flavell, 1973; Schleien, Kiernan, & Wehman, 1981).

Normalization, age-appropriateness, and student preferences are three important considerations in the selection of recreation activities (Putnam, Werder, & Schleien, 1985). Microcomputer based recreation activities score high in relation to each of these concerns. Furthermore, the ease of incorporating adaptations which enhance independent performance is another valuable characteristic.

In the context of computer games, other valuable skills can be taught or practiced. Switch based activities provide an excellent context for motor skill development. For many students, voluntary control over the depression and release of a switch can be practiced during computer activities (e.g., Frog and Fly--Motor Training Games; Switchmaster--Expert Systems Software, Inc., 1985). For students who have some proficiency at switch use, a program called "The Scanning Game" provides an enjoyable activity in which a child learns to coordinate visual scanning with the activation of a switch. Different versions of the game allow teachers to provide instruction individually or in a small group. In small group instruction, the game can be structured by the teacher so that during each student's turn, he or she is responding to stimuli presented at an individualized speed and level of difficulty. In other video games, the use of a joystick provides practice in "reaching and grasping," skills often difficult for students with physical impairments.

As a context for integration, computer games provide an activity in which both handicapped and nonhandicapped students can enjoy themselves. Once again, the ability to use peripherals to enhance a student's ability to participate in this task is an asset that can be exploited by teachers. In addition to the use of switches and/or adapted joysticks, the Adaptive Firmware Card has a Slow Down function which enables a teacher to regulate the speed of a game. Through the construction of custom menus, teachers can use the Adaptive Firmware Card to allow students access to computer games through a single switch rather than a joystick or the keyboard.

Program Management and Support Activities

At the school and district level, there are many areas into which microcomputers are effectively integrated in an information management system (Ragghianti & Miller, 1982). The following discussion will be limited to management and support applications which occur at the classroom level.

Data management. In order to meet the accountability requirements of P.L. 94-142 and provide quality instruction, teachers are faced with significant paperwork and management tasks. Monitoring student progress and making data-based instructional decisions for every student are two of these responsibilities which require substantial time commitments from the teacher. At least two software programs (Cruscial & Schimmer, 1983; Hasselbring & Hamlett, 1983) have been designed to assist teachers in this area. According to study reports, computer managed instruction results in a 25 to 30% saving of time over manual methods of performing the same tasks (Baumgart & VanWalleghem, 1984; Detwiler, 1982). For purposes of illustration, the features of AIMSTAR (Hasselbring & Hamlett, 1983) will be described.

AIMSTAR was designed to assist teachers in providing data-based instruction. Using this program, teachers enter program descriptions, instructional methods, and student performance data. Once entered, teachers can obtain printed reports and a graphic display of student performance data. The charted data are compared to a student's "aim rate," a line of progress calculated on the basis of a student's start and anticipated completion date of instruction. Furthermore, data can be analyzed in relation to precision teaching decision rules developed by Haring, Liberty, and White (1981). From messages that are generated, based on the student's rate of progress, the teacher will know if instructional changes are warranted. If instructional changes are made, the program file is updated. Thus, a report that provides an instructional chronology can be generated.

Word processing. Close collaboration between home and school is an essential component of quality instruction for students with severe handicaps (Bates, Renzaglia, & Wehman, 1981). Teachers frequently rely on written communication to maintain close contact with families. For teachers who type, a word processing program can facilitate this task. In a sample of 12 teachers of students with severe handicaps participating in a pilot computer project, 100% indicated that they found the computer useful in generating reports and letters (McGregor, 1986).

Decision-Making in the Use of Technology

It is easy to get caught up in the novelty and attractiveness of technology, so that its use becomes an end in itself rather than a means to an end (York, Nietupski, & Hamre-Nietupski, 1985). Several questions are raised to assist in determining whether a computer is the appropriate means of performing a given task.

- Is the task educationally valid? An over-infatuation with technology can cause a user to structure activities on the basis of what is currently available rather than educational validity. In instructional applications, the overriding concern is the educational importance of the task. Is the skill/activity in question one that is part of the student's IEP? Has this skill/activity been determined to be important in increasing participation in current and future environments?

- Will the computer activity reinforce skills that are learned in other contexts? Generalization problems are characteristic of students with severe handicaps. A common teaching strategy to address this problem is to train sufficient exemplars (Stokes & Baer, 1977). If computer activities are closely integrated with training provided in other contexts, the chances of skill generalization are increased.

- Is the computer time efficient? For both management and instructional applications, the question of time efficiency is relevant. If computers can be successfully used to perform a task in the same or less time as traditional methods, their use is warranted. If not, they need to offer some other advantage over traditional means in order to justify the greater time and expense required.

SUMMARY

Microcomputers are a new and available technology for special educators. For individuals concerned with services for low incidence populations, the microcomputer's ability to utilize even a student's small response and provide output in a variety of modalities is a great asset. Its usefulness in relation to response-contingent learning, choice making, communication and environmental control, as well as recreation and leisure skill development has been discussed. Furthermore, the facility with which computers store and manage information can be applied to the many management and recordkeeping tasks associated with the provision of special education. Used within a context to enhance special education services rather than dictate them, computers will prove to be a great asset in providing quality services in programs for students with severe handicaps.

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Computer Resources

Single Switches

Prentke Romich
1022 Heyl Road
Wooster, OH 44691
(216) 262-1984

Computability Corporation
101 Route 46 East
Pine Brook, NJ 07058
(201) 882-0171

Don Johnston Developmental Equipment
981 Winnetka Terrace
Lake Zurich, IL 60047
(312) 438-3476

Switch Interface/Input Boxes

In order to attach a single switch to the Apple computer, a switch interface device must be connected to the computer in the Game I/O receptacle. Switch interfaces which accommodate either single or multiple switch inputs can be purchased or constructed. The commercial vendors listed above under "Switches" also sell interface devices.

A specialized input device, called the **OMNIBOX**, has been developed by:

Expert Software, Inc.
923 Van Leer Drive
Nashville, TN 37220
Cost: $249.00

Once again, input boxes can be made at home for a fraction of the cost of commercially distributed devices. Directions for a Four Hole Switch Input Box can be obtained from: Project ACTT, 27 Horrabin Hall, Western Illinois University, Macomb, IL 61455.

Adaptive Firmware Card

Adaptive Peripherals
4529 Bagley Avenue, North
Seattle, WA 98103
(206) 633-2610
Cost: $395.00

Unicorn Board

Unicorn Engineering Company
6201 Harwood Avenue
Oakland, CA 94618
(415) 428-1626

Keyboard Shields

Adaptive Technology, Inc.
5334 72nd Circle, North
Brooklyn Center, MN 55429

Touch Window

Personal Touch Corporation
4320 Stevens Creek Boulevard
San Jose, CA 95129

A RESPONSE

Samuel C. Ashcroft

A wealth of practical information in the context of eminently helpful theoretical perspectives is provided in the papers by Dr. Scadden and Dr. McGregor. A remarkable amount of both practical information and theoretical perspectives apply equally well to students who are visually impaired and those who are multiply handicapped. Both papers provide information which can help in assessing the state of the art in their respective domains. They can also assist in closing existing gaps between the state of the art and the status of practice.

Larry Scadden has provided an admirable review of the state of the art and the "Impact of Technology on Visually Impaired Children and Youth." He has used the best available sources. His list of references for further information on these topics will be of benefit to the readers. My response to the Scadden paper reflects the perspective of one who has been directly involved with the programs, developments, activities, and publications he has reviewed. Some ideas included in this paper are available in greater detail in a recent CEC-ERIC Monograph (Ashcroft 1986) titled Alternative Futures in Special Education. It focuses on current and future trends through reports on our research with visually impaired students.

Scadden and McGregor documented the need for technology in the lives of visually impaired and multihandicapped persons both through their reviews and through insights gained from their personal experience. As they indicated, the need is urgent. Actually, it cannot be overstated if persons with vision and other handicaps are to participate in and benefit from the information explosion and the information society that accompanies it. As Scadden says, no single group may benefit more than visually impaired persons.

Among the best additional evidence that these developments are significant and expected to have an impact on visually impaired and multihandicapped individuals is the sudden, unprecedented proliferation of private enterprise, for-profit activity and competition in the field. No other era nor other area of services or product development, particularly in the history of work for the blind, has excited such attention and activity. A list of more than 20 sources of relevant products and information which illustrates the point is appended to this response.

If visually impaired and multihandicapped persons and those who live and work with them are to benefit from these dramatic changes in today's way of life, the status of special educational practice must get closer to the state of the art in technology. There is now a wide discrepancy. The gap is great! Can special educators manage to close it or will it inevitably continue to widen? What shall be done?

High priority must be given to changing special educators' own attitudes and expectations. We must overcome our own techno-phobia. Each individual must become computer and technology literate at least to the extent of using the tools in everyday life and in teaching. "Computer literate" means being able at least to do word processing, to access data bases, to use user friendly programs on microcomputers and to operate devices like the Versabraille and the Kurzweil Reading Machine. "Technology literate" means being able to use, without "morbid fear," the simple devices described by Dr. McGregor. These criteria are not stringent, but they are still too infrequently met by teachers who work with visually impaired and/or multihandicapped students. Yet, they are readily achievable by any qualified teacher.

Realistic expectations must be set and achieved for teachers and for special education students, as well as for technology per se. Among the most difficult problems faced by handicapped persons themselves and the significant others who live and work with them is setting and attaining realistic goals and expectations. People who are blind are constantly plagued by unrealistic expectations, their own and those of others. This situation prevails because their own expectations are an interactive outcome of the expectations of others they have encountered--expectations too low, too high, too frequently unrealistic. Such unrealistic expectations are usually born of lack of experience and insufficient contact with visually impaired persons. Similarly, special educators' expectations for technology are often unrealistic--too low, too high, or otherwise unrealistic. These expectations too, when unrealistic, are born of lack of experience and contact with the technology. There is need to learn through experience to set expectations that will challenge but will not frustrate.

Attempts have been made to predicate the research and development work that has been done with microcomputers and access technology on realistic expectations for visually impaired persons, for technology, and for our own capabilities. Therefore, our research has been guided by validated principles derived from a theoretical perspective. The intention has been to create "situations of just manageable difficulty" that enable optimum growth toward independence for the learner. Thus, technology is applied to overcome discrepancies between environmental expectations and demands and the capabilities of the person with a handicap. Concurrently, effort is being made to increase the capabilities of the individual so he or she can effectively meet increasingly greater and more natural environmental requirements. Technological devices and the necessary means of access are provided to create an effective interface between the person and the equipment for effective functioning in such natural environments. If guided by these principles, it seems possible to avoid developing over-dependence on technology, on teachers, and on oversimplified environments while learning to set realistic expectations.

There are interesting parallels between the state of the art Dr. Scadden reports, our research, and the work of the program for multiply handicapped children reported by Dr. McGregor. As she points out, there has been a useful shift in emphasis from more specifically focused developmental perspectives to functional perspectives. The criterion of ultimate functioning and the involvement of multihandicapped children to the greatest possible degree, or an approximation to independence, provides more realistic goals and aspirations toward which to work. Enhancing performance in operant skills and providing for the establishment and acceleration of alternative skills are worthy incremental steps toward increasing independence. Such a perspective parallels special educators' aspirations for students with single handicaps, that is, without the complication of additional impairments and disabilities as found in multihandicapped students.

If students are to learn to cope with "situations of increasingly manageable difficulty" in today's complex information society, they must be linked with information technology, especially microcomputers and the access technology that makes them accessible. For blind students, first priority should be given to keyboard skills, word processing, and to accessing data bases and then to opening the world of other possibilities in computer assisted instruction (CAI) and learning. Let CAI be a secondary priority until effective and accessible software comes along or until the field can develop the specially designed software uniquely needed for visually impaired learners. Guidelines have been proposed for some of the features that should characterize such software. For multiply handicapped children, as Gail McGregor says, "We need to provide training that utilizes real materials and naturally occurring cues and consequences in the context of functional activities in integrated settings."

For teachers, of both visually impaired and multiply handicapped students, it is necessary to use computers to manage instruction and to assist with the difficult teaching tasks to be faced. It is also part of the teacher's task as role model to demonstrate to students that we value technology and what it can do for teaching, learning, and vocational and career opportunities. Every Individualized Educational Program (IEP) should have a technology component and a technological perspective indicating how available technology can assist and facilitate learning and instruction no matter what level of functioning nor how simple or complex the instructional goals.

There is urgent need to cooperate and network with those who are knowledgeable and are implementing effective programs. McGregor's paper indicates that there are innovative and exciting programs that are applying technology within well-conceived theoretical frames of reference and with down-to-earth practicality that brings significant performance progress for complex multihandicapped children. Typically, those who develop and implement these programs are eager to share them and are gratified to have us seek their help. It is wasteful to "reinvent the wheel" and to struggle where others have developed answers. Technology can help enormously with such networking through the SpecialNet Bulletin Boards on Vision and Technology, through User Groups, and through data bases.

Teachers must know currently available resources as well as those in the process of development. It is important to let those who are providing materials know the urgency of special educators' needs and the strength of their interests. There is an exciting and unprecedented growth of sources of information, equipment, and programs. The entrepreneurs and service providers need to know what is and is not helpful in the instructional programs being implemented. The attached list is a sampling of the rapidly expanding sources.

In the face of the Gramm-Rudman-Hollings legislation and other threats to funding, it is urgent that special education professionals work for local, state, and national resources and for public and private funding for the needed equipment and programs. National resources such as the American Foundation for the Blind, the American Printing House for the Blind, the Association for the Severely Handicapped, the Technology and Media Division of CEC, the Association for Special Education and Technology, and others need to be told how urgent our needs are and of their obligation to respond.

The future is bright but there is urgent need for concerted action in terms of realistic expectations of visually impaired and multihandicapped persons, expectations of professionals, expectations of the technology which has so much promise for improvement of instruction, and expectations of the agencies committed to this field. It will take the best efforts of all of us to reduce the gap between the state of the art and the status of our practice. It may be a "just manageable difficulty" if we work hard enough.

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A Sampling of Resources for Technology for Visually Impaired and Multihandicapped Persons

(November, 1986)

Prepared by S. C. Ashcroft, Peabody College, Vanderbilt University, Nashville, TN 37203.

American Foundation for the Blind, National Technology Center, 15 W. 16th Street, New York, NY 10011. (800) 232-5463

American Printing House for the Blind, 1839 Frankfort Avenue, Louisville, KY 40206. (502) 895-2405

Apple Talk, Jeff Weiss, 3015 S. Tyler Street, Little Rock, AR 72204

Apple has just opened an Office of Special Education, Apple Computer, Inc., MS23D, 20525 Mariani Avenue, Cupertino, CA 95014

Association for Education and Rehabilitation of the Blind and Visually Impaired, Suite 320, 206 N. Washington Street, Alexandria, VA 22314

BAUD, Audio Tech Laboratories, 1158 Stewart Avenue, Bethpage, NY 11714. (516) 433-0171

Closing the Gap, P.O. Box 68, Henderson, MN 56044. (612) 248-3294

Computer Aids Corp., 124 W. Washington, Lower Arcade, Fort Wayne, IN 46802. (800) 647-8255

The Council for Exceptional Children, Technology and Media Division (TAM) and Division for the Visually Handicapped (DVH), 1920 Association Drive, Reston, VA 22091. (703) 620-3660

Mark Corp., P.O. Box 15321, Westford, MA 01886. (617) 692-8570

Maryland Computer Services has now pooled resources with Triformation Systems, Inc. Write MCS/Triformation Systems, 3132 S.E. Jay Street, Stuart, FL 33497. (305) 283-4817

Microcomputer News for Teachers of Blind Students; Quarterly $5.00. Catherine Mack, Computer Resource Center, Florida School for the Blind, 207 N. San Marco Avenue, St. Augustine, FL 32084

Multiple Services Media Technology, Inc., 1000 4th Street, Suite 390, San Rafael, CA 94901. (415) 454-6768

Optelec, Optical and Electronic Applications Specialists, 325 Ayer Road, Harvard, MA 01451. (671) 772-9269

Raised Dot Computing, 408 S. Baldwin Avenue, Madison, WI 53703 (608) 257-9595. Braille Edit

Sensory Aids Corporation, 205 West Grand Avenue, Bensonville, IL
60106. (312) 766-3935. Technology UpDate and Sensus

SpecialNet, National Association of State Directors of Special Education,
Suite 610E, NEA, 1201 16th St. NW, Washington, DC 20036
(202) 833-4193.

SPEECH Enterprises, 10622 Fairlane Drive, Houston, TX 77024.
(713) 461-1666

Telesensory Systems, 455 North Bernardo Avenue, Mountain View, CA
94043. (800) 227-8418

The Visual Field, Florida Instructional Materials Center, 5002 N. Lois
Avenue, Tampa, FL 33614

VTEK, 1625 Olympic Boulevard, Santa Monica, CA 90404. (800) 345-2256

CLOSING REMARKS

Vivian I. Correa

Collaboration has been defined as the complex interplay of talents and knowledge that come together at appropriate times to produce a commonly valued end result which no single party could ever have produced alone (Lanier, 1980). The 2-day symposium was truly a collaborative experience. No single speaker, respondent, participant, division president, or CEC staff member could have produced a successful symposium independently. The collaborative efforts put forth served to establish greater commitment and motivation for improving educational services for low incidence handicapped children and their families.

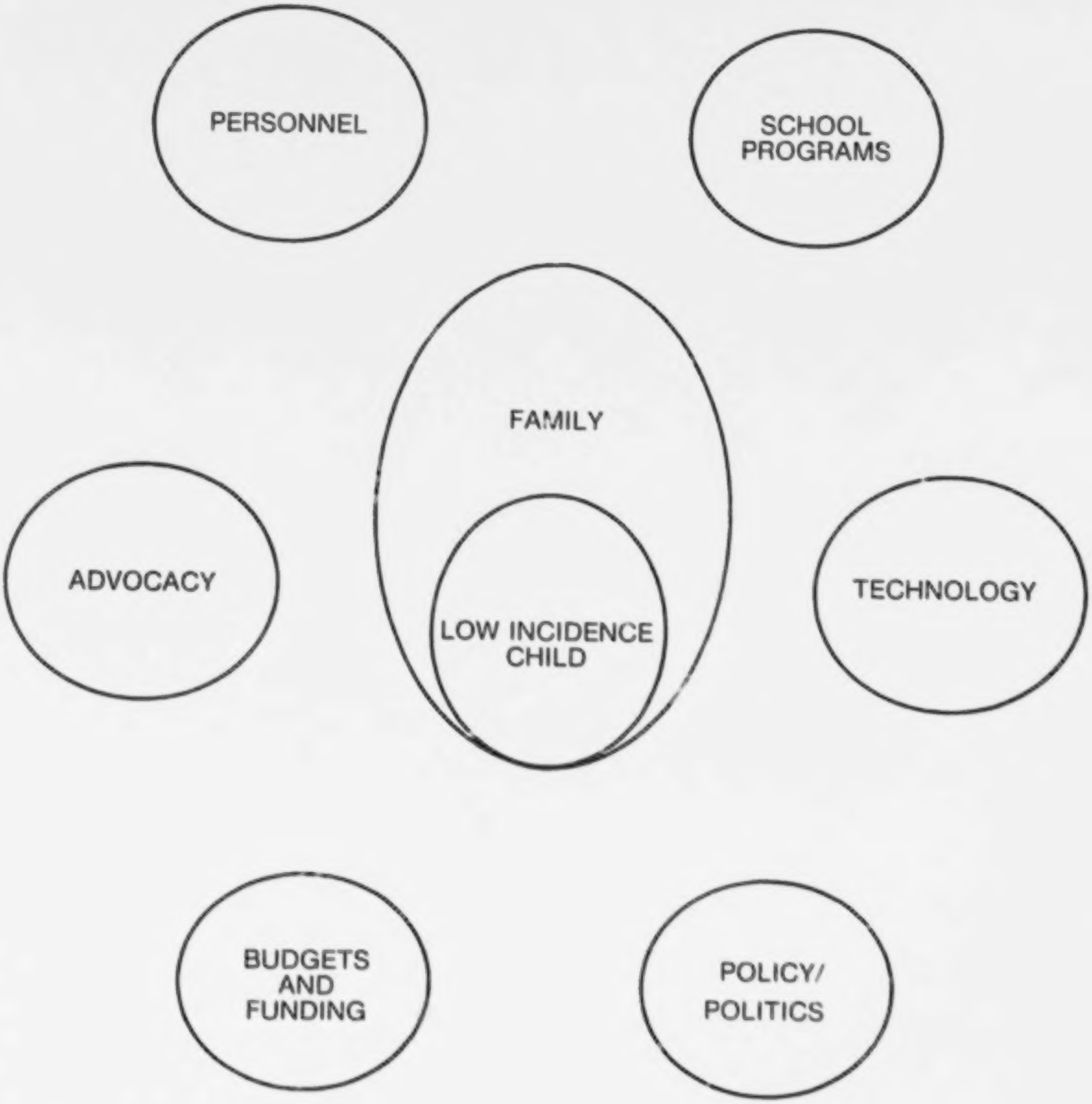
The purposes of these closing remarks are to summarize and synthesize the content discussed during the 2-day symposium. To encapsulate the information, a systemic theoretical approach was used to conceptualize the issues related to educating low incidence handicapped children. Figure 1 illustrates the use of a systems analysis for conceptualizing many of the issues raised during the symposium. The Reactive Paradigm Model, as presented in Figure 1, represents the interaction of variables influencing the education of low incidence handicapped children.

Systemic thinking guides us to understand that each subsystem (e.g., budgets, personnel, technology) is an integral part of the total system. No one subsystem functions independently. Thus, the goal for intervention with low incidence children is to have a system that is well-balanced, cohesive, and harmonious. Yet, according to much of the discussion presented at the symposium, the systems in which the participants are working appear to be disengaged, fragmented, and perhaps chaotic. In describing services for medically fragile students within public school settings, Shell (1981) asked the question: Are we straining the system? The question is relevant for many special educators who are presently trying to serve low incidence children within subsystems that are not supportive or are essentiallly nonexistent.

The model presented illustrates the various components of serving low incidence children. Although each component of this system is necessary for providing quality education for low incidence children, the total picture changes when looking at rural, urban, or suburban geographic environments. Therefore, the Reactive Paradigm Model not only serves as a means of summarizing the issues related to low incidence populations, but potentially may serve as a tool for the evaluation and analysis of individual programs across the nation.

Perhaps the critical question to ask is: Why are we straining the system? By looking at each of the variables discussed during the symposium, we can begin to analyze which components of our own low incidence system are weak, nonfunctional, or nonexistent. The following section will review each of the areas discussed during the symposium. Issues and solutions presented by each of the speakers, respondents, and discussion groups will be incorporated.

FIGURE 1
The Reactive Paradigm Model


PERSONNEL
SCHOOL PROGRAMS
FAMILY
ADVOCACY
LOW INCIDENCE CHILD
TECHNOLOGY
BUDGETS AND FUNDING
POLICY/ POLITICS

Issues in Serving Low Incidence Populations

THE CHILD WITH A LOW INCIDENCE HANDICAP

During the course of the symposium, a critical question emerged: Who is the child with a low incidence handicap? Do we need an official definition of low incidence handicapped children? Can that definition allow the flexibility to include students with vision, physical, communication, and multiple impairments? Do adequate prevalence and incidence data exist to support the contention that there is a rise in the numbers of low incidence handicapped children? Perhaps there are no clear answers to these questions, but it is clear that problems arise when each subsystem (i.e., component) defines or interprets the low incidence child in a different way.

In the case of the medically fragile child, the participants discussed the importance of developing guidelines and criteria for deciding whether the student should be assigned to a classroom, homebound instruction, or a hospital program. Further, they asked for specification of parameters of the educational program for a medically fragile child. For example, they asked what part medical intervention plays in educational programming. Repeated questions dealt with the roles of medical and educational personnel working with these students.

In the case of the medically fragile child, it was suggested that answers to some of these questions might be generated through the efforts of a task force or interest group which could begin to define the many issues raised during the conference discussions. It is apparent that the participants are in the forefront of bringing attention to the medically fragile child. As Blackston stated, health and education professionals must coordinate services in order to provide quality support for both families and children. Defining all variables of the system serving the medically fragile child is a start in the clarification of the many relevant interactions and program needs.

THE FAMILY

A theme which undoubtedly surfaces in any discussion of handicapped children is status of the family. Not surprisingly, this theme clearly emerged over the 2-day discussions. It is apparent that the role of the family in the education of the low incidence handicapped child is critical. The family's need to become informed and involved in all aspects of their child's education was highlighted in each of the presentations. Families with medically fragile children need support from both health and educational professionals. In turn, professionals must communicate honestly and effectively; they need to provide the family with realistic expectations for their child. Professionals must assess each family's level of coping on an individual basis and provide counseling that meets the family's needs. Furthermore, a genuine respect for families must be established, including a respect for the cultural background and socioeconomic level of each family. Lastly, the issue of respite for families was discussed. Often, the extraordinary demands placed on the family (e.g., medical costs, daily care, therapy services) may cause "burn-out" of the persons involved.

During the discussion of advocacy, the role of the family in assuring a lifelong education for their child became a key issue. With the movement toward governmental mandating of early childhood services for handicapped children, the focus on family involvement will become more critical. In fact, the Reauthorization Act of 1986 supports the use of individual family service plans for children under 2 years of age.

Additionally, the participants expressed their concern that families may have little power in making decisions relevant to their child's education. For example, Weintraub suggested that families may need advocates to protect them from some other advocates. At times, even the best intentions on the part of a family's advocate may still not prevent them from choosing inappropriate services. Providing a variety of well-defined options and a continuum of service models will give families more variables to consider when making a decision about their child's education.

Similarly, the concern over informing families about technology was evident during the sessions on technology. Families are often advised to provide their child with "high-tech" materials, only to find that the equipment or devices purchased are not functional for the child at home.

There is no doubt that the family is a complex system within itself. Through analyzing the role of the family within the paradigm illustrated in Figure 1, the professional can be in a position to center all intervention around the needs of both child and family.

PERSONNEL WORKING WITH LOW INCIDENCE CHILDREN

The training of professionals working with children who evidence low incidence handicaps became one of the major focal points of the symposium. A number of issues relating to personnel preparation were discussed.

Teacher shortages and recruitment issues in both local school districts and institutions of higher education (IHEs) received much attention during the conference. In particular, rural and inner-city school districts are encountering difficulty in attracting teachers to their communities. When the schools are fortunate enough to find a teacher willing to work with low incidence students, that teacher is often unqualified and in need of inservice training or continuing education. Not surprisingly, Helge (1983) found that 66% of special education teachers in rural school districts were on emergency certificates. Added to this already grave situation is the issue of serving the medically fragile child within the school system.

Only recently have IHEs begun to offer infant specialist programs that address the needs of medically fragile children. Yet, abundant unanswered questions remain: What skills must a teacher possess to meet the needs of these special children? Will teachers need skills in minor medical procedures such as trachiostomy suctioning or gastrostomy feeding procedures? Will it be necessary to offer university practicum experiences in neonatal intensive care units? Are there university faculty equipped to offer courses and supervise internships in these areas? Are professional preparation programs ensuring that teachers have skills and knowledge necessary for collaboration with other team members? Often, the teachers are called upon to consult with and prepare others to work with the medically fragile and low incidence student. Are they competent to do so?

Innovative models for teacher training are needed. Infusing already existing college curricula with new content (e.g., medically fragile children, collaboration, consultation) may be a solution. Additionally, cross-disciplinary training (e.g., nursing, physical therapy, occupational therapy) may be necessary for teachers who wish to work effectively with medically fragile children.

These issues are critical ones confronting university teacher training programs today. Once again, the question is: Are we straining the system?

Colleges of education are in competition for student enrollments with colleges of business, medicine, engineering, and others. How can education, and in particular, special education, compete with professions that pay higher salaries and offer a higher professional status? The solutions to student recruitment at the university level are not simple. Anne Corn shared her nontraditional ideas on recruitment (e.g., publishing a letter in "Dear Abby"). Another more traditional method mentioned during the discussions was recruiting regular education teachers for special education training.

Strong pleas were made for further research in the area of low incidence handicapped children. Universities as well as state and local agencies must be encouraged to conduct empirical studies to further investigate this population and its educational needs.

Each subsystem must play a part in providing adequate support for serving low incidence children. Perhaps far more than any other subsystem, personnel preparation issues may be the most critical in meeting the demands set forth at this symposium.

SCHOOL PROGRAMS

This aspect of the symposium discussion centered around the curricular needs of students and the concept of a continuum of service delivery models. The idea of "lifelong" curricula was discussed on a variety of levels. "Lifelong" curricula was seen as essential in providing low-incidence students with an education that prepares them for the next environment and culminates in successful integration into the facets of society (e.g., vocational, community, social, and recreational). Unfortunately, for students who evidence serious medical impairments, the appropriate curriculum is not as clear. Issues on teaming, medical procedures, and assessment measures as related to the development of curriculum materials for medically fragile students were also discussed during the symposium.

Similarly, the issue of innovative service delivery models for low incidence children was discussed. There is support in the literature for such innovation (see Helge, 1983; Hollingshead, 1985; Zeph, 1983). A continuum of least restrictive environment (LRE) service delivery options must be considered. The above authors suggest creative ways by which a variety of low incidence students can be mainstreamed into public school programs. For example, Helge (1983) proposes 10 models for rural service delivery for special education students and provides guidelines for considering the model best suited for the individual school district. Often, the itinerant teacher model is the one used for serving low incidence handicapped children, because school districts find it difficult to justify one full-time teacher for two or three low incidence children (e.g., visually impaired).

Although the itinerant teacher model is one solution, it has its problems. Maars (1983) pointed to the estimated 30-50% attrition rate in rural schools. He attributes the high percentage to the stress and extraordinary demands placed on itinerant teachers. Often, teachers must travel long distances to reach schools in rural areas. The travel time is usually considered downtime. Additionally, traveling in rough terrain or inclement weather can add to teacher stress. Also, the itinerant teacher may see little evidence of child progress when her or his intervention schedule is sporadic and there is a lack of reliable follow-up. Perhaps the pros outweigh the cons on this issue. Nonetheless, there is need for sensitivity to Maars' (1983) observations and consideration of these factors when establishing itinerant service delivery models for low incidence children. Special educators are limited only by our imagination and creativity regarding the continuum of options available for low incidence children and their families.

ADVOCACY AND POLICY/POLITICS

These components of the Reactive Paradigm Model illustrated in Figure 1 fall under the general category of government. The symposium participants identified issues related to advocacy and policy for low incidence populations. Weintraub provided an inspirational presentation on the need for establishing a "mission" for the "new generation" of special education students. The mission should include lifelong educational goals for preparing students and their families for the next environment. Legislation, such as the HR55-20 Amendment, (education for handicapped students from birth to 5) can aid in achieving the new mission, but laws cannot do it alone. Efforts must continue with increasing emphasis toward improving the quality of curricula, personnel, and service delivery models.

BUDGETS AND FUNDING

According to Shell (1981) some school districts report spending four times as much on special education for low incidence students than for nonhandicapped students. Shell also reports that the Houston school district spent $9,000 in order to refit one school van to carry a medically fragile student to school. The van contained an emergency life support system, including oxygen and suction equipment and a back-up power system for respirators.

Education of low incidence and medically fragile students is expensive and is likely to become more costly due to advances in technology. For example, Scadden spoke of access technology for visually impaired learners that could cost over $10,000. Communication boards and electronic devices presented by McGregor could cost over $3,000, and adaptive equipment for a single child could easily exceed $7,000 when it includes a travel chair, standing table, tilt table, and a wheelchair-adaptable desk. There is no doubt that programs for low incidence children are among the highest cost components in the field of special education. It seems clear that this component of the system is being strained. One solution suggested by the symposium group focused on the need for collaboration with the private sector (e.g., local businesses, foundations); such suggestions included direct community involvement in activities such as walk-a-thons. Furthermore, the group discussed the need for lobbying in order to increase funding in the areas affecting low incidence children.

TECHNOLOGY

The last issue addressed at the symposium was devoted to technology for low incidence children. Scadden and McGregor presented information on current technology available for visually impaired and multihandicapped students. The group discussions centered around the issues of cost and training. As mentioned in the previous section, technology for low incidence children is costly. Finding ways to involve corporate business (e.g., IBM, Apple Computers, Tandy, Citicorp) in subsidizing the purchase of high-tech equipment would be advantageous in a variety of ways. Additionally, school districts' establishing networks with centers of training or rehabilitation facilities could aid teachers and parents with equipment needs.

Lastly, training personnel in the use of access technology was discussed as a critical component of both preservice and inservice training programs. Teachers require competence in evaluating access systems for individual students, and parents will need to play a major role in the decision-making process.

CONCLUSION

The educational needs of students with low incidence handicaps are complex. A variety of support systems must be available in order to provide quality education for these students. This paper has attempted to encapsulate the critical issues discussed during the CEC Low Incidence Symposium. The 2-day symposium served to reaffirm the commitment to improving the quality of education for low incidence children.

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